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PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT (P.L. 99-319)

HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

on

EXAMINING PROPOSED LEGISLATION ON THE REAUTHORIZATION OF THE PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT (P.L. 99-319)

MAY 10, 1988

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PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT (P.L. 99-319)

TUESDAY, MAY 10, 1988

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The Subcommittee convened, pursuant to notice, at 2:36 p.m., in Room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (Chairman of the Subcommittee) presiding.

Present: Senators Harkin, Weicker, Stafford, and Simon.

OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. The Subcommittee on the Handicapped will come to order.

The purpose of this hearing is to determine what changes, if any, need to be made in the Protection and Advocacy for Mentally Ill Individuals Act of 1986, which was signed into law on May 23, 1986.

Before hearing from the first panel, I'd like to again congratulate Senator Weicker, the former Chairman of this Subcommittee, for investigating the problems of abuse and neglect of individuals with mental illness in facilities, for introducing S.974, and for managing the bill through the legislative process.

Because of the bill, we now have a protection and advocacy system for mentally ill individuals in every State.

As the new Chairman of the Subcommittee on the Handicapped, I will in the future, as I have in the past, work closely with Senator Weicker and his staff and other members of the Subcommittee in developing a bipartisan consensus bill reauthorizing this very important piece of legislation.

The staffs of the members of the Subcommittee have been meeting over the last several weeks, and they are developing recommendations for ways of improving the legislation.

We look forward to hearing from the witnesses, and we also look forward to reviewing the written testimony presented by others, including the National Institute of Mental Health, which administers this program and which was invited, but chose not to testify at the hearing.

[The prepared statement of Senator Harkin follows:]

OPENING STATEMENT OF TOM HARKIN
CHAIRMAN, SUBCOMMITTEE ON THE HANDICAPPED
HEARING ON THE REAUTHORIZATION OF THE PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT OF 1986

In 1984, Senator Weicker, the then chairman of the Subcommittee on the Handicapped, commissioned a staff investigation of the care and treatment of, among others, individuals with mental illnesses who were inpatients or residents in facilities.

The staff report documented dangerous conditions and "a climate of fear and intimidation" in 12 states and 31 facilities. The staff report concluded that: "Abuse and neglect of society's most vulnerable citizens must stop. Care and treatment must be provided in an atmosphere of dignity and respect. And those to whom this care is entrusted must be held fully accountable." The report drew attention to the fact that mentally ill individuals who were inpatients and residents in facilities did not have access to the same type of protection and advocacy services available to individuals who are developmentally disabled.

Following the submission of the report, the Subcommittee held hearings, at which the witnesses confirmed the findings of the staff report. Following the hearings, Senator Weicker introduced S. 974, authorizing the establishment of a system of protection and advocacy for mentally ill individuals in each state. The bill passed the Senate on July 31, 1985; a companion bill passed the House on January 30, 1986; the Senate and the House worked out their differences in May of 1986; and the President signed the bill into law on May 23, 1986.

Under the Act, the systems' mission includes protecting and advocating for the rights of mentally ill individuals and investigating incidents of abuse and neglect of mentally ill individuals who are residents or inpatients in facilities rendering care or treatment.

In addition, the Act authorizes the system to pursue allegations of abuse and neglect arising within 90 days after the client's discharge from a residential facility. The system is required to maintain the confidentiality of patient records to which it gains access.

The entity operating the system is the same entity that operates the protection and advocacy system for the developmentally disabled under the Developmental Disabilities Bill of Rights and Assistance Act. However, the system is encouraged to cooperate and subcontract with other mental health advocacy organizations in the state.

Each system is required to establish an advisory board including attorneys, mental health professionals and providers; at least half must be consumers and their family members.

Although the Act was authorized for three fiscal years--1986 through 1988, the first fiscal year saw no activity. The Act was passed in May and grant awards were issued in September. As of May 1, the program has only been operational for 19 months. Therefore, in light of the newness of the program, it is my intent to entertain changes to the legislation that reflect a fine-tuning or changes that reflect issues which clearly were not adequately addressed in the Act. We need more time before we make fundamental changes to the legislation.

Senator HARKIN. The opening statements of Senator Simon and Senator Stafford will be inserted in the record at this point.

OPENING STATEMENT OF SENATOR PAUL SIMON

Senator SIMON. Mr. Chairman, I was among those who sat on this subcommittee and listened to the testimony that led to the enactment of the legislation we are reauthorizing. We had a staff report, the product of nine months of investigation and on-site inspections of 31 facilities for mentally handicapped persons. I shared the dismay of my colleagues over the reports of fear, intimidation, neglect and abuse that gave us reason to doubt that we have progressed far in our attitudes toward the mentally ill or in our ability to serve them.

In fact, we do have facilities today that are models of our ability to restore the mentally ill to productive life. They show that we have made progress—and their existence makes the continued warehousing, abuse, and neglect of those not privileged to be in the best facilities all the more inexcusable.

The enactment of this law was recognized as one small step we could take to begin to address these pervasive problems. It is too soon to expect that great inroads have been made toward changing systems that foster abuse—particularly where the heart of the problem lies in the failure to put adequate funds into the system. But I am heartened by the reports that individual lives are being changed and helped by the dedicated people who work for the Protection and Advocacy for the Mentally Ill (PAMI) program.

Although there has not been much time to assess the impact of this Act or the need for changes, I know there are some useful suggestions that have been made to build on the base provided through this Act. I look forward to the testimony and to the further strengthening of a vital piece of legislation.

OPENING STATEMENT OF SENATOR ROBERT T. STAFFORD

Senator STAFFORD. Mr. Chairman, I want to commend you for holding this oversight hearing as we reflect upon this important legislation and its impact on the lives of persons with mental illness as we start the task of reauthorization. Two years ago Congress passed the Protection and Advocacy for Mentally Ill Individuals Act. This legislation followed several investigations into the abuse and neglect of individuals residing in this Nation's public and private institutions for mentally ill persons.

The original protection and advocacy system enacted over ten years ago in the Developmental Disabilities Act has provided thousands of disabled individuals with the assistance needed to help them to achieve a better quality of life through continuing to live in their own communities. So, too, the P and A system for individuals with mental illness, even though in its infancy, has benefited these people by providing them with an organization which will ensure that their rights to appropriate services and a good, safe and clean environment are maintained.

Senator HARKIN. Before I call on the first panel, I would recognize my distinguished colleague, Senator Weicker.

Senator **Weicker**. I thank Senator Harkin very much for his kind remarks. I have a statement prepared, which I will ask be entered in the record, and again, my appreciation to him for holding these hearings. I am certain that whatever it is that we achieved a few years back, we can improve upon it before we are all through, thanks to the effort and willingness of our witnesses to come forth and testify.

Thank you.

[The prepared statement of Senator Weicker follows:]

STATEMENT OF SENATOR LOWELL WEICKER, JR.

HANDICAPPED SUBCOMMITTEE HEARING ON THE REAUTHORIZATION OF PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT

MAY 10, 1988

THIS AFTERNOON WE WILL HEAR TESTIMONY ON THE REAUTHORIZATION OF THE PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT OF 1986. AS MANY OF YOU KNOW, THIS LAW WAS PASSED IN RESPONSE TO THE APPALLING CONDITIONS IN STATE FACILITIES FOR THE MENTALLY ILL WHICH WERE UNCOVERED DURING A SIX-MONTH SENATE INVESTIGATION AND THREE DAYS OF HEARINGS BEFORE THIS SUBCOMMITTEE.

DURING THE COURSE OF THOSE HEARINGS, AND IN SITE VISITS TO 31 FACILITIES IN 19 STATES, TWO FACTS BECAME ABUNDANTLY CLEAR. FIRST, MENTALLY ILL INDIVIDUALS LIVING IN THOSE FACILITIES WERE SUBJECT TO ABUSE AND NEGLECT. SECOND, THOSE INDIVIDUALS OFTEN DID NOT HAVE ACCESS TO ADEQUATE REPRESENTATION OR ADVOCACY TO REMEDY THE ABUSE AND NEGLECT THAT BEFELL THEM. THE SYSTEMS THAT DID EXIST TO PROTECT MENTALLY ILL PERSONS WERE TYPICALLY UNDERSTAFFED, OVERLOADED WITH CASES, AND MANY TIMES, WERE STAFFED BY EMPLOYEES OF THE VERY ENTITY THAT HAD PERMITTED THE ABUSE AND NEGLECT TO OCCUR.

AS THE HEARINGS THAT EXPOSED THIS SHOCKING SITUATION CAME TO A CLOSE, IT HAD BECOME PAINFULLY EVIDENT THAT, INSTEAD OF BEING TREATED WITH DIGNITY AND RESPECT, THESE INDIVIDUALS WERE BEING DEPRIVED OF THEIR MOST FUNDAMENTAL RIGHTS. CLEARLY, ACTION HAD TO BE TAKEN TO ENSURE THE PROTECTION OF THE RIGHTS OF THESE INDIVIDUALS, AND ALLOW THEM TO RECEIVE TREATMENT IN AN ATMOSPHERE FREE FROM ABUSIVE AND NEGLECTFUL CONDITIONS.

SHORTLY THEREAFTER, I INTRODUCED S.974, TO CREATE AN INDEPENDENT, FEDERALLY-FUNDED SYSTEM OF PROTECTION AND ADVOCACY FOR MENTALLY ILL PERSONS IN EACH STATE. AFTER THIRTEEN MONTHS OF LENGTHY NEGOTIATIONS WITH THE ADMINISTRATION, SERVICE PROVIDERS, CONSUMERS, AND ADVOCATES, THIS BILL BECAME LAW. WITH ITS ENACTMENT, A SYSTEM WAS ESTABLISHED TO AFFORD MENTALLY ILL PERSONS ASSISTANCE TO HELP THEM SECURE THEIR RIGHTS GUARANTEED UNDER FEDERAL AND STATE STATUTES AND THE U.S. CONSTITUTION.

IT HAS NOW BEEN TWO YEARS SINCE THAT LEGISLATION WAS SIGNED INTO LAW, DURING WHICH TIME THIS SYSTEM BECOME OPERATIONAL IN EVERY STATE. AND, AS WE WILL HEAR TODAY, THERE ARE REFINEMENTS THAT CAN AND SHOULD BE MADE, INCLUDING A SUBSTANTIAL INCREASE IN THE AUTHORIZED LEVEL OF FUNDING IF THE PROGRAM IS TO SERVE ALL THOSE WHO NEED IT.

PRELIMINARY DATA REGARDING THE PROGRAM INDICATE THAT PROTECTION AND ADVOCACY SYSTEMS AROUND THE COUNTRY HAVE HAD AN ACTIVE YEAR, SERVING A TOTAL OF 9,758 CLIENTS LAST YEAR THROUGH BOTH INDIVIDUAL PROTECTIVE ACTIONS AND SYSTEMS ADVOCACY CASES.

I WISH I COULD REPORT THAT THE DEPLORABLE CONDITIONS UNCOVERED DURING THE INVESTIGATION THREE YEARS AGO HAD BEEN TOTALLY ERADICATED AS A RESULT OF THE PASSAGE OF THIS LAW. UNFORTUNATELY, DESPITE THE VALIANT EFFORTS OF THE PROTECTION AND ADVOCACY SYSTEMS, THEIR SERVICES ARE NEEDED AS MUCH AS EVER TO ENSURE THAT MENTALLY ILL PERSONS DO NOT SUFFER INJUSTICE AT THE HANDS OF A SYSTEM THAT IS SUPPOSED TO HELP THEM.

THE FACT IS THAT THERE IS STILL A GREAT DEAL OF WORK TO BE DONE BEFORE WE ARE COMPLETELY SUCCESSFUL IN REACHING ALL OF THOSE INDIVIDUALS WHO REQUIRE ADVOCACY AND ASSISTANCE. THE REAUTHORIZATION OF THE PROGRAM THIS YEAR ALLOWS US, WITH THE HELP OF THE INDIVIDUALS AND ORGANIZATIONS REPRESENTED BY THE WITNESSES TODAY, TO EXAMINE WAYS TO ENHANCE THE PROTECTION AND ADVOCACY AGENCIES' CAPABILITIES TO SERVE THE NEEDS OF THEIR CLIENTS.

AND, AS WE ADDRESS THE PRINCIPAL ISSUES OF INCREASED ACCESS TO FACILITIES AND THE NEED FOR ADDITIONAL RESOURCES, WE MUST KEEP IN MIND THE CONSUMERS--BOTH PATIENTS AND THEIR FAMILIES. THEIR

LIVES WILL BE TOUCHED IN A VERY REAL WAY BY WHAT WE DO HERE TODAY AND IN THE WEEKS AHEAD, AND WE MUST ACT TO STRENGTHEN THEIR ABILITY TO FIGHT FOR THE RIGHTS GUARANTEED THEM BY OUR CONSTITUTION AND OUR LAWS.

I AM LOOKING FORWARD TO HEARING FROM TODAY'S WITNESSES AND ESPECIALLY WOULD LIKE TO WELCOME ELLIE KOHN, WHO IS HERE FROM CONNECTICUT TO REPRESENT BOTH THE NATIONAL MENTAL HEALTH ASSOCIATION AND THE MENTAL HEALTH LAW PROJECT. ELLIE HAS BEEN A TIRELESS ADVOCATE FOR THOSE WITH MENTAL ILLNESS AND THEIR FAMILIES, BOTH IN CONNECTICUT AND HERE IN WASHINGTON.

THANK YOU, AND I LOOK FORWARD TO WORKING WITH ALL OF YOU AS THE REAUTHORIZATION PROCEEDS.

Senator HARKIN. Our first panel includes William Snavely, President of the National Alliance for the Mentally Ill, from Arlington, Virginia; Joe Rogers, President of the National Mental Health Consumers' Association, in Philadelphia; and Dayna Caron, National Alliance of Mental Patients, Johnson, Vermont.

I'd like to ask you each to briefly summarize your statements in five to seven minutes. If the lights work, we will turn them on; if they do not, I'll try to give the time, but 5 to 7 minutes, if you could summarize each one, and I will call upon you in the order I introduced you.

Senator WEICKER. Now that I'm no longer Chairman of the Committee, my job after 5 minutes is to vault over the dais here and tackle you to the floor if you don't end your statements. [Laughter.]

Senator HARKIN. All right. Mr. Snavely, welcome, and please proceed.

STATEMENTS OF WILLIAM W. SNAVELY, PRESIDENT, NATIONAL ALLIANCE FOR THE MENTALLY ILL, ARLINGTON, VA; JOSEPH ROGERS, PRESIDENT, NATIONAL MENTAL HEALTH CONSUMERS' ASSOCIATION, PHILADELPHIA, PA, AND DAYNA H. CARON, NATIONAL ALLIANCE OF MENTAL PATIENTS, JOHNSON, VT

Mr. SNAVELY. Thank you. Chairman Harkin, Members of the Subcommittee, my name is Bill Snavely, and I am President of the National Alliance for the Mentally Ill, and we are very happy to be here and have this opportunity of speaking to you this afternoon.

The National Alliance for the Mentally Ill currently has over 65,000 members and 800 affiliates. We were very supportive of the original legislation that established the protection and advocacy agencies. We are broadly supportive of the current amendment that is being considered, particularly those provisions of the amendment that have to do with strengthening the Advisory Council and membership on the Governing Board of the protection and advocacy agencies.

I am not going to read my statement, but I have three points I'd like to just briefly cover in my remarks.

The first is with regard to the provisions of the bill that deal with the detention of an individual, the transportation of a mentally ill person to a treatment facility to a commitment hearing, we believe that this language is useful because it basically addresses many of the complaints that we have had from our members throughout the country in which they report evidences of substantial abuse in this area, either by the arresting officers or personnel of a treatment facility in which excessive force has been used, resulting in some cases in the death of mentally ill individuals or serious injury to our loved ones. So we think this is an important provision of the law.

However, we do not endorse the idea that the protection and advocacy agency should involve itself in the actual commitment hearings themselves. We believe there is adequate protection in the State laws and State procedures that govern this.

So we would like to see as part of the bill a specific exclusion of the protection and advocacy agency in the area of the actual commitment hearings per se.

The second point is the abuse and neglect of persons that are in the jails and the prisons. We would have liked to have seen these persons addressed in the law itself. We would have liked the present draft expanded to include persons in the jails or the prisons as a population that would be covered by the protection and advocacy law.

It is our conviction that one of the negative consequences of deinstitutionalization is that many, many mentally ill persons are being inappropriately incarcerated in jails simply because there are not adequate treatment facilities or adequate community services available. Mentally ill persons are jailed inappropriately as a consequence and labelled as criminals.

Those fortunate enough to have treatment available to them in the jails are still subject to the potential of abuse, neglect and violence against their persons and, of course, against their dignity.

Unfortunately, many of these facilities offer no treatment, which simply compounds the problems.

So while we believe that the proposed study by the GAO to look at this population, to identify the problems and some of the model programs is useful and we endorse the study, we ask your consideration of possibly expanding the coverage of the law to this particular population. It is a very, very large problem for many of the mentally ill and their families.

Finally, there is the question of budget availability to the advisory councils. We have had problems with the staffs of some protection and advocacy agencies who have refused to make available the budgets for those protection and advocacy organizations on the basis that budgets are private information or that budgets are not something that is appropriate for advisory councils and/or advocacy groups to have.

Obviously, budgets tell a lot about what is going on in a particular agency and in a particular program. We feel it is appropriate, that these documents are in fact public documents, and they should not be accorded any particular protection under the proprietary provisions of contracts with private organizations that are rendering these particular services.

We would like to see in the language of the report acknowledgment that these are public documents and should be made available to the Protection and Advocacy Advisory Councils and to the advocacy groups concerned.

In conclusion, we endorse the amendments that have been offered; we strongly support the one that relates to the role of the Advisory Council and how it participates in the actual development of policies and priorities, and we ask consideration for the additional recommendations included in my written statement.

Thank you very much.

Senator HARKIN. Thank you very much, Mr. Snavely.

[The prepared statement of Mr. Snavely follows:]

STATEMENT OF WILLIAM W. SNAVELY, PRESIDENT, NATIONAL ALLIANCE FOR THE MENTALLY ILL, BEFORE THE SUBCOMMITTEE ON THE HANDICAPPED, U. S. SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES, MAY 10, 1988:

Chairman Harkin, Members of the Subcommittee:

The National Alliance for the Mentally Ill (NAMI), a national self-help network for families of persons with mental illnesses, greatly appreciates the opportunity to share with you our views concerning the reauthorization of PL 99-319, the Protection and Advocacy for Mentally Ill Persons Act of 1986. Our 65,000 family members and 800 local affiliates were strong supporters of the original legislation and we are pleased to be here today to endorse the basic outlines of the amendments contained in the reauthorization proposal.

Since its enactment, PL 99-319 has been subject to close monitoring by our members and other mental health advocacy groups. As a result of the initial experience in implementing the Act, we believe protection and advocacy services for persons receiving care and treatment for mental illnesses in residential facilities can be strengthened through the amendments offered for your consideration this afternoon. The amendments incorporate essential features of a position paper jointly developed by a coalition of the major advocacy organizations and we commend you and your staff for your responsiveness to our concerns.

We are particularly gratified by your efforts to empower families and consumers of services with a greater role in the governance and establishment of priorities for protection and advocacy agencies. NAMI believes that Congress intended such active involvement from the beginning, but notes that practice has varied among the states with regard to the degree of consultation between the advisory boards (which must be at least 1/2 family and consumer members) and governing bodies (which are not currently required to have any family or consumer representation). The amendments being proposed go a long way toward assuring meaningful participation by the advisory boards in the process of implementing the Act.

While we endorse the draft proposal on reauthorization, we would like to offer some suggestions and comments for your further reflection:

1). On page 2 of the draft bill, lines 19-22, the language is overly broad. This was a recommendation of the coalition to deal with situations in which a person might be abused while being taken into custody or transported for commitment to a treatment facility. We have had numerous cases reported to us in which a person was subjected to unnecessary or questionable use of force by peace officers or treatment staff--sometimes even resulting in death or major injury. But it was not the intent of the coalition to include within the ambit of this provision any intervention by a protection and advocacy agency in commitment proceedings per se. We believe there are ample procedural safeguards under current state laws to govern the judicial hearings preceding commitment and would ask that such hearings be expressly excluded from the application of Section 102 (2) (C).

2). On page 3 of the draft bill, at lines 17-20, we interpret the language to mean that there must be at least the chairperson of the advisory council on the governing board, but that representation from consumers and advocates for persons with mentally illnesses would not be restricted to that sole individual. To us, "broadly representative" implies some degree of proportionality of representation and inclusion of the chairperson of the advisory council by statutory reference should not reduce the obligation under the "broadly representative" provision to assure a balanced composition of the governing authority.

3). On pages 3-4 of the draft bill, reading from lines 23-24 through lines 1-3 on page 4, we believe the "jointly develop" provision should be strengthened and clarified to grant the advisory council some formal approval authority with regard to the annual priorities. A case can be made that the draft proposal contains other mechanisms for advisory council leverage, but we have received a significant number of complaints about governing bodies ignoring the advice and counsel of advisory boards. An advisory council sign-off on priorities would promote greater coordination and cooperation and prevent a repetition of past misunderstandings.

4). NAMI is delighted with the creative concept embodied in Section 5 of the draft and congratulates the Subcommittee and its staff for making the P & A system more accountable through this reporting mechanism.

5). On page 4, beginning at line 23, NAMI would prefer to see the Congress directly confront the problem of abuse and neglect of persons with mental illnesses residing in Federal facilities, state prisons, and local jails and lockups, rather than mandating another study. We are convinced that one of the negative consequences of deinstitutionalization without adequate community services is criminalization of persons with mental illness. Too many persons with mental illnesses are incarcerated in correctional facilities in lieu of treatment and other required community services. For those fortunate enough to receive some treatment, the environment still poses significant opportunity for abuse, neglect, and violence against their person and their dignity. For the larger number who receive no treatment in the correctional setting, the problem is compounded. In fact, we believe the absence of treatment constitutes de facto abuse and neglect for persons with brain diseases and is simply intolerable in a just and civilized society.

With regard to Federal facilities, NAMI agrees with Representative Waxman's view that Congress never intended to exempt Veterans Hospitals from the jurisdiction of protection and advocacy services. The VA today constitutes the largest system of psychiatric hospitals in the nation. It seems contrary to the avowed purpose of PL 99-319 to hold this system immune from application of the law.

In fact, our preference is for the jurisdiction of the protection and advocacy system to be client-centered, rather than residential site limited. If a person who is mentally ill is being abused or neglected in any residential care setting, the P & A should have authority to investigate or intervene in an appropriate way.

If this Subcommittee cannot endorse this approach, then we urge you to retain the G. A. O. study feature as a means of keeping the very real problems of these frequently invisible victims of abuse and neglect in our consciousness.

6). On page 6, at lines 8-13, we agree that assurances need not be submitted annually, because we do not want small agencies overburdened with duplicative paperwork. But, at the same time, we believe it is vital to preserve the right of consumers, families, and other advocates to challenge an agency if compliance with the assurances is not evident. We would recommend modification of this provision to permit the Secretary to require additional assurances for good cause.

7). In some states, confusion has arisen about the public nature of the P & A budget under PL 99-319. In some cases, agency staff have refused to permit inspection of the budget documents by advisory boards and/or advocacy organizations. We believe these basic documents are public information not covered by the proprietary rights of private, non-profit systems designated to carry out the law. While it may not be necessary to clarify this confusion in statute, we do believe it is important to address the issue in report language. Public access to budgets should be a central feature of the accountability of all quasi-public P & A systems.

In conclusion, Mr. Chairman, the National Alliance for the Mentally Ill joins its colleagues in the advocacy community in urging the Subcommittee to reauthorize the Protection and Advocacy for Mentally Ill Individuals Act with the amendments presented in the draft document. Together with the suggestions we have offered, the Subcommittee bill provides a blueprint for a more effective system--one in which consumers and families can have confidence. We offer you our support and look forward to working with you and your staff on any additional refinements you deem desirable.

Thank you for this opportunity to share our views with you.

Senator **Harkin**. Before I turn to Mr. Rogers, I would just welcome Senator Stafford to the Subcommittee. If you have an opening statement or anything else, Senator Stafford, you are welcome to proceed.

Senator **Stafford**. Thank you very much, Mr. Chairman.

In the interest of time, I do have an opening statement, and I would ask unanimous consent that it appear in the record at an appropriate place.

Senator **Harkin**. Without objection.

Thank you.

Next is Mr. Joe Rogers, President of the National Mental Health Consumers Association.

Welcome, and please proceed.

Mr. **Rogers**. Thank you very much.

The last time I appeared before this Subcommittee, Senator Weicker was still the Chairperson, and at the time we were so enthusiastic about this bill and still are so enthusiastic, we said we would give Senator Weicker our endorsement, the mental patient vote, if he wanted to run for President. He didn't take us up on that, and I don't know if that would carry very far, but in the future maybe. And Senator Harkin, maybe you could run, and we would have a nice balanced ticket there.

The situation, I think, in the couple of years now that we have talked about in the development of this program is one of a mixed situation in that we are here today to, I think, hopefully, make a better program.

The program is in many ways a very successful program. In Pennsylvania, where I come from, we have been able to really establish for the first time a Statewide, coordinated effort of advocating for the needs of the mentally ill. For the first time throughout the State of Pennsylvania, the agenda of protecting the rights of the mentally ill is on the table, and people are really beginning to take it seriously, and I think a large part of that is due to the fact that we now have a Statewide protection and advocacy system.

There are still some issues that concern us throughout the Nation. The biggest one for us in the consumer movement and expatient movement is that we who have been victimized in the State hospitals, as Senator Weicker knows from the hearings that he held that initiated this bill, are very concerned that there be provisions that really allow us to have a voice in the implementation of these programs.

What we have found so far in the relatively small amount of time that we have been doing the work is that to really be effective in advocacy, it is very difficult for professional advocates who, for the most part, are outside, not really able to be in the programs; if they are in the programs, if they are in the hospitals, they are not there usually 24 hours a day.

When I was in a hospital in Florida, the abuses and problems took place usually at 3:00 in the morning, and there were no advocates available, and even to this day, if you call the 800 numbers, and there are tons of 800 numbers that have developed because of this bill, you call those 800 numbers and you get an answering machine.

One of the ways, we feel, to address that is by training and involving people themselves, the folks who are at risk, having some understanding of what their rights are and understanding how to advocate for themselves.

So one of the provisions we are supporting in the reauthorization language is for subcontracting to consumer organizations.

The other issue, in this short of amount of time that I have to discuss this, is the issue of the money. Obviously, the funds that we have to do the job are not really adequate. In Pennsylvania, we have over 16 State hospitals to deal with. Somebody asked me what can we say to the Senator in terms of when they are looking at a budget—I understand you are going right from this hearing to an appropriations hearing, where you are going to be fighting with defense and farm and everybody else for the kind of dollars that we are talking about. Well, one thing I would like to offer as something in your arsenal of fighting for this funding and the additional funding that we are asking for is that actually you are talking about a relatively cost-effective program in the sense that when you have advocates in the community advocating for the best services, advocating for the most appropriate services—and we haven't really yet documented it—but we have actually seen a shift in the kinds of services mental patients are getting. You generally see a shift from the institutional services to more appropriate community services—and I mean appropriate community services, not dumping on the streets, as we have seen in the past.

And what you get is you actually get a cost savings. In our State, it is estimated at $70,000 per year per mental patient in a State hospital. We have actually been able through our program to impact on the system so that those people who are inappropriately in State hospitals could be out of the State hospitals, and you actually realize a savings.

On the train down here, I realized that if we get 20 people out of our State hospital and more appropriately placed in community services, you are realizing a savings for the taxpayers of $20,000 to $30,000 per person in our State. So the three hundred and some thousand dollars that is spend on P&A services in our State actually pays not only in terms of human care and human rights being protected, but in terms of making things more efficient and more appropriate in the kinds of care that the mentally ill get.

So there really is a cost benefit analysis, I think, that could be done on this program that hasn't really been done, and I think it would be interesting to really look at that issue.

The issue for us in terms of involving the consumers goes to the heart of what we think needs to be done. It is not just a nice thing to do; it is not just something that you do because you kind of want to pay off some individuals.

My experience as an advocate has been that families and consumers are the ones who are going to carry the ball in the community and develop a constituency for advocacy services.

I think because of the limited funding that we are able to commit to this program on the Federal level, my understanding and my feeling is that this in some ways is seed money, and how can you increase this seed money—we feel by developing a constituency and involving consumers and family members develops a constituency for advocacy services that in many ways can begin to double the impact and power of the program.

I thank you for the opportunity to testify.

Senator **HARKIN**. Mr. Rogers, thank you very much.

[The prepared statement of Mr. Rogers with attachments follow:]

Testimony of
Joseph A. Rogers, President
National Mental Health Consumers' Association
311 South Juniper Street, Room 902
Philadelphia, PA 19107
215-735-6367

Senate Committee on Labor and Human Resources
Subcommittee on the Handicapped
430 Dirksen Building, Washington, DC
May 10, 1988

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*Due to printing limitations and in the interest of economy, these documents were retained in the files of the committee.

My name is Joe Rogers. I am President of the National Mental Health Consumers' Association, the first national organization of present and former mental patients. I am here to convey to you my concern about the issues before us today regarding the reauthorization of the Protection and Advocacy law and, in particular, Protection and Advocacy issues of special concern to consumers.

As a consumer -- one of those Congress intended to be involved in the activities of the Protection and Advocacy system -- I want to thank the Senate subcommittee for this opportunity for consumers to testify on the issues that are vital to us in the reauthorization of the Protection and Advocacy for Mentally Ill Individuals Act.

As we consumers understood the P&A law, it required that Advisory Boards be established and have an advisory role in setting the "policy and priorities" for the P&As; it mandated consumer and family involvement as at least 50 percent of the Advisory Boards; and it encouraged P&As to "consider entering into contracts" with organizations already providing P&A services. As consumers, we were -- and still are -- delighted to be included in the P&A process in this formal way. We believe that the P&A law is working well for many consumers across the country in protecting us and in advocating for our rights. We are concerned, however, that in some areas P&As are not being as effective as they might be in protecting and advocating for consumers and their rights. I will be commenting later about the particular need for investigations and additional monitoring by P&As to fully protect consumers from abuse, neglect and even death. Consumers can do and are doing monitoring and investigation for P&As elsewhere that are fulfilling their obligations in these areas for protecting consumers.

Our real hope now is that by rewriting some of these key provisions, we can help make the P&As work even better in involving consumers and family members in protecting us all under the law.

We also want to emphasize our support for a realistic increase in funding for the P&A programs, particularly if the present coverage of the Act is clarified to include federal facilities, local jails and prisons, and persons in the admissions process. As we see the present situation, P&As are already strained financially trying to meet their statutory duties. In my own state, Pennsylvania, the P&A must cover 16 state institutions and a myriad of local facilities. Working jointly, our Governing and Advisory Boards have set facility monitoring, consumer empowerment and case advocacy as our P&A priorities. However, without increased funding, we are now being forced to consider cutting back or even eliminating some of our major initiatives in these critical areas. We agree with the request of Carol Garvin (upcoming president of the National Mental Health Association) to the House for funding increases:

- FY 1989, $22.0 million
- FY 1990, $25.0 million
- FY 1991, $30.0 million.

This would permit the P&A programs for the mentally ill to operate on a par with those for people with developmental disabilities.

As a member, and chairperson, of the Mental Health Advisory Board to Pennsylvania Protection and Advocacy, Inc., and as a member of its Governing Board, I am aware of how well the P&A law can really work to assure meaningful consumer and family involvement. At Pennsylvania P&A, we have both consumers and family members on an active Advisory Board that regularly proposes and approves projects to our Pennsylvania P&A Governing Board. We have constantly strived to involve more consumers and family members at both the Advisory Board and Governing Board levels. In Pennsylvania, we have made a successful transition from a developmental disabilities-specialized organization to one truly focused both on developmental disabilities and mental health issues. We have entered into subcontracts with consumer and family advocacy organizations to train consumers and family members and to monitor our state hospitals, and we have an excellent relationship with both local and statewide consumer and family groups.

That is the good news. However, in addition to knowing how well we are doing in Pennsylvania, I also know that we have been very fortunate as consumers and family members in Pennsylvania compared to some other P&As.

As I mentioned, one of my other "hats" is that I serve as President of the NMHCA, the first national organization of present and former mental patients. I have personally consulted with, trained and visited with over a dozen P&As or consumer groups involved with P&As from Florida to Vermont. At national and regional meetings and conferences over the past year and a half, I have met with consumers, family members and P&A staff and board members to talk about what is happening with the P&As across the country. At the NMHCA, I and other members hear "the good, the bad and the ugly" about what's happening with the P&As across the country. As a P&A Advisory Board member and consumer attending the P&A training sessions and meetings in St. Louis and elsewhere, I see and hear the comments and criticisms of consumers, family members and, yes, even P&A staff from other states and territories. I want to emphasize here that I don't want to overstate the level of concern. Just as in Pennsylvania, there are other P&As that are responsive to consumers -- for example, in Arkansas, in Alaska, in Wyoming and elsewhere. Many P&As are really struggling to involve more consumers and family members, to set up subcontracts with existing consumer and family organizations.

However, the reason I'm here today is not the P&As that are out there really doing or trying to do what the law intended them to do. The reason I'm here today is that we need changes in the law to encourage real consumer and family involvement in some P&As that are actively or passively resisting their legal obligations.

Just for one example, in a Midwestern state, a single consumer was nominated to the Governing Board, where his every question or proposal has been ignored. He specifically questioned -- as many of us have -- the use of mental health P&A funds or overhead for activities largely devoted to the developmental disabilities side. He questions the low level of activity by the P&A in regard to its legal responsibilities in protecting and advocating for mental health consumers. He and we are not saying that the developmental disabilities end of Protection and Advocacy isn't important and valid; it's just that mental health funds should be spent on P&A for the mentally ill.

We also want to talk about the P&A in one of Pennsylvania's neighboring states, Delaware. We at the NMHCA have been actively trying to assist the consumers, the Mental Health Association and the P&A in this state. We were told at one point last year that the Advisory Board required by the law was not being established because the P&A Director did not want "anyone telling her what to do." The consumers in this small state, as well as a staff member, came to us asking for our help and seeking advice on what to do. Quinn Rossander, a consumer advocate from Delaware, has submitted an affidavit that addresses these concerns specifically. See the affidavit attached hereto as Appendix A.

We know that in a large Northwestern state, the P&A resisted involving consumers in the Advisory Board or in subcontracting. Laura Van Tosh, a consumer now in Pennsylvania, formerly from Washington state, has already submitted an affidavit to the House subcommittee describing this situation. See the affidavit attached hereto as Appendix B.

We know of a Western state where the P&A refused to convene the mental health advisory board until a consumer hired a lawyer and gave notice of his intention to bring suit. "Everything is fine, now," he reports.

In another, New England state, consumers had a major subcontract with their P&A, only to have such major administrative problems that they have terminated the relationship. See Portland Coalition Advocate Newsletter, attached hereto as Appendix C.

In another, Southern state, in an effort to technically comply with the letter, yet evade the spirit, of the P&A law, not one but four advisory boards were set up with only one staff member total and a single joint annual meeting. By multiplying the provider and other non-consumer or family members, and by isolating the four advisory groups both from each other and the governing board, the P&A has mathematically complied with the meaning of the law while completely undermining the intent of involving consumers and families in the P&A.

The litany goes on. In one of our largest states, the Governing Board is a state agency which includes no consumer and/or family members. The P&A spends most of its money on conferences and reports, not on active advocacy. The same situation exists in other states' P&As "governed" by state agencies. Consumers in a neighboring state -- where I and other members of our organization have a long history of consumer activity -- complain that they have been systematically ignored when their Advisory Board proposes programs to the single-person director of the agency. There is no appeal or even a formal mechanism for reviewing or rejecting their proposals. Bill Butler, a consumer from New Jersey, has submitted an affidavit addressing these concerns specifically as well as particularly troubling issues of concern to New Jersey consumers regarding the well-publicized recent rash of patient deaths and injuries in their state hospitals. See affidavit attached hereto as Appendix D.

The issue for us as consumers is not just that we're being excluded or ignored by some P&As, however. The real issue is that those few P&As that have not complied with the spirit of the P&A law -- by involving consumers and family members in governing and advisory boards, and through subcontracts -- are losing valuable, cost-efficient resources. I've already mentioned the Pennsylvania P&A's reliance on consumer groups and subcontracts. In Wyoming, Maine, Georgia and elsewhere, consumer and family groups are doing training, monitoring and advocacy. Our affiliated national consumer consulting group, CONTACT (Consumer Oriented National Technical Assistance Consulting and Training), has pioneered the creation of a consumer training manual for use by P&As, particularly in large rural states with small populations. This manual was written by consumers for P&As in such areas. See the preliminary draft of manual, attached hereto as Appendix E. Right near here in Maryland, a consumer group has initiated its own hospital monitoring and consumer drop-in center program. These are all good examples of how P&As

can benefit from involving and subcontracting with consumers.

Finally, on this issue of consumer involvement around the country in P&As, consumers at a recent national consumer teleconference discussed their impressions of P&A responsiveness to consumers. Of the consumers from 15 states making comments, eight different states were critical of their P&As for not involving consumers, or ignoring them if they were involved at all. A typical comment came from Ohio, where consumers complain that the P&A doesn't return calls and has not been active in its work. (See Appendix F, attached.) In Michigan, consumers similarly complain about their P&A's inaccessibility and unresponsiveness. (See Appendix G attached.) Consumers representing states on the teleconference had complaints very similar to those of these other states about which you have heard today in affidavits and statements.

For all of these reasons, we support the following amendments to the P&A law as part of its reauthorization as proposed by the P&A Coalition that has been meeting since early this year: the requirement of a P&A governing board "broadly representative" of its clients that includes the Advisory Board chairperson and which jointly develops an annual statement of P&A priorities with its Advisory Board; new language insuring P&A access to records on dead or missing patients and to discharge planning sessions; clarifications regarding P&A coverage of federal facilities and local jails and prisons, as well as coverage of the admissions process; and a provision for annual reports, comments and grievance procedures. We support the new language in the bill encouraging P&A subcontracting with consumer and family groups, for the reasons already given.

We also support new administrative language proposed by the P&A

Coalition for requiring more appropriate use of technical assistance funds by the Secretary in accordance with the expressed needs of the P&A system. Many P&As -- like the Maine P&A -- are not getting or giving the technical assistance that we as consumers need when we do have P&A subcontracts. In order to provide cost-efficient P&A services, relevant technical assistance must be made available from NIMH, rather than merely obscure legal research or other such services. (All of the Coalition proposals are attached hereto as Appendix H.) We should comment here that the staffing of the NIMH P&A office has been a problem for us as consumers and for many of the P&As that we have visited. The NIMH P&A office is clearly understaffed and undersupported administratively. We need more competent and informed staff administering the P&A program at NIMH in order to assure the program's continued viability. Staff with specific backgrounds in mental health program delivery and governmental administration have been in short supply for this program in particular.

There is one other concern that I feel I must emphasize today to this committee. Over the last two weeks -- since the House P&A reauthorization hearing -- we have had several instances where consumers have felt that they were being pressured as a result of their giving testimony and/or affidavits to the House. We are very concerned about the apparent bad faith of those P&A officials and others who may have tried to influence ourselves and the other consumers who have chosen to speak out about problems with some of the P&As across the country.

We strongly believe in the First Amendment -- our right to free speech and to petition our governmental representatives -- to seek redress of our grievances. We object to any attempt to interfere with consumers' right to free speech by pressuring them at their P&A Advisory Boards and

Governing Boards, at their jobs, at their groups and in their local communities. If there were any serious question about our facts or our motives -- and we submit there can be none -- this hearing is the proper place for that debate, not through back channels back home. We ask that this subcommittee take notice of our concern about any attempt to censor or silence our people, or to retaliate or recriminate against us once these hearings are over. I think it's sad that these kinds of things are happening to people to whom so much has already happened and whose vulnerability is the whole point of the P&A law. These problems only demonstrate how much we need the additional protections proposed in this bill.

As I've already said, we are not here today trying to "trash" the P&A system: we believe it is working well, and with good results and the best of intentions in many areas. We want to work with the National Institute of Mental Health, the National Association of Protection and Advocacy Systems, the National Alliance for the Mentally Ill and the other "players" to help make the P&A "movement" work as well as possible for all of us. We believe that the reauthorization is not so much a "hassle" as it is a real opportunity for us to improve on the existing law -- to clarify its purposes, improve its procedures and guarantee that all of us have a voice in its future as was intended under the original legislation. Thank you, again, for the chance to present our views here today.

APPENDIX A

Affidavit
of
Quinn D. Rossander
601 West 19th Street
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302-652-2204

Pertaining to the Reauthorization of Public Law 99-319
The Protection and Advocacy for Mentally Ill Individuals Act of 1986

Presented before the
Senate Committee on Labor and Human Resources
Subcommittee on the Handicapped
430 Dirksen Office Building
May 10, 1988

I, Quinn Rossander, being of full age and duly sworn, do hereby affirm and depose as follows:

1. I am a mental health consumer from the state of Delaware and an organizing member of the H.O.P.E. Chapter of the Mental Health Consumers of Delaware, which I will tell you about in a moment. First, I want to provide some background about the difficulty we are encountering in establishing and involving consumers in an effective Protection and Advocacy program in Delaware. I also want to note specifically that I am speaking only for myself and not as a representative of any group or organization.

2. Delaware's Mental Health Protection and Advocacy program has been operated by the Disability Law Program of the Community Legal Aid Society, which for the past 10 years has been providing legal services to some mentally ill or emotionally impaired people in Delaware who had developed such conditions prior to the age of 22.

3. Unfortunately the quality of care provided to the mentally ill of Delaware is very poor and still focused heavily on state hospital incarceration. Delaware has most recently been evaluated by Drs. Torrey and Wolfe as rating 47th in the nation in the quality and extent of mental health services provided to its citizens. The Delaware State Hospital itself is currently operating on a contingency approval plan from the JCAH accrediting program since its quality of medical care is so marginal.

4. It was therefore with great anticipation that Valerie Tonwe, Esq., was brought on board in January of 1987 as the first person hired specifically for what we as consumers hoped would be a new dawning for Delaware in mental health care through the P&A program. (See, e.g., Exhibit 1, "The New Arrival," an article from The Stigma, a publication of

H.O.P.E.) Mrs. Tonwe proved to be a capable worker, as can be seen from the attached letter to the American Civil Liberties Union, dated July 1987, accurately describing the present Delaware Involuntary Commitment Law as "absolutely horrible." (See, e.g., Exhibit 2.) Unfortunately, due to personal health problems, Mrs. Tonwe is presently on extended sick leave from the program.

5. In the Fall of 1986, as members of the state Mental Health Association, we began to organize a Mental Health Consumer Movement and involved Project SHARE from the National Mental Health Consumers' Association to help us start a local organization. With this support, a group of mental health consumers called H.O.P.E. was organized in Delaware in February of 1987. Our group has grown and flourished with presently an active membership of more than 50 members with two chapters meeting regularly and we are now in the process of incorporating under Delaware Law.

6. Last summer our group began contacting the Community Legal Aid Society in order to participate in the Mental Health Advisory Board of the P&A program. We learned at that time that there was no such Board and by local and national pressure we were able to start meeting to communicate with Chris Long, the Program Director in Delaware for the Mental Health P&A Program. After repeated telephone calls and several meetings and supported by the Mental Health Association of Delaware and the National Alliance for the Mentally Ill in Delaware, we were at last able to persuade the Program Director of our interest and credibility as a consumer group.

7. On October 31, 1987, we finally had our first meeting with NAMI, the Mental Health Association and the Program Director to try and

start our Advisory Board. As of this date, it does not appear that all of the mandated positions for the Mental Health P&A Advisory Board have been filled. We have since October met three times as a group to try and move in support of the importance of input to the daily operating priorities of the P&A program.

8. As you can see from our experiences in Delaware there is no perceived priority or importance to the Mental Health Protection and Advocacy Advisory Board and until very recently we have had no input to the Governing Board of the Legal Aid Society. As you can see from my letter to the Program Director (see, Exhibit 3, attached), we, as members of the P&A Board, have still been given no information on the operation or funds thus far spent on this program in Delaware.

9. As consumers we see the development of community services as having the highest priority. Sadly, this has not been reflected in the group or class-action suits referred to the ACLU, which is the main focus of P&A legal activity thus far in Delaware.

10. We are very proud, however, of the fact that we have a patient advocate working at the Delaware State Hospital through P&A funding to the Mental Health Association of Delaware. Already just his presence alone on the hospital grounds has caused a greatly improved attitude toward patient care and resulted in more humane treatment by hospital staff. Unfortunately, however, there has also been a great deal of controversy about the patient advocate program (see, e.g., Exhibit 3 attached), which hopefully now has favorably been resolved so that he will continue to provide his services to the mental health consumers of our state.

11. Finally, I want to tell you about what has happened to me

since the House hearing on Monday, April 25. Following my appearance, two weeks ago, before the House of Representatives, I received calls beginning Tuesday morning from the Program Director of the Mental Health P&A program requesting copies of the material presented in the Hearing before Representative Waxman and asking that I attend the P&A Advisory Board meeting rescheduled for Wednesday, April 27, which I had previously indicated I could not attend due to another commitment.

12. In light of the House Hearing, and the concern expressed by the Program Director in her phone messages Tuesday and Wednesday asking that I attend the P&A Advisory Board and/or make available to her a copy of my testimony in Washington, I cancelled my previously scheduled meeting for that Wednesday and attended the P&A Advisory Board meeting instead.

13. Two attorneys were present at this Advisory Board Meeting, one being introduced to the Advisory Board as a liaison person from the Governing Board to the Advisory Board. This was the first time such a position had even been referred to, let alone that anyone had appeared bearing such a title, and so came as a complete surprise. Thus, for the first time in Delaware, we now have an official member of the Governing Board who will be attending our Advisory Board meetings. When asked how this person was selected, it was explained that she volunteered for the position. Her presence and position was a complete surprise to the Advisory Board as no prior mention of such a position had ever been made.

14. In place before each seat at the Advisory Board meeting table on April 27 was a 12-page copy of the P&A report to the National Institute of Mental Health dated December 31, covering the period from October 1, 1986, to September 30, 1987, which I had previously requested from the Program Director in a letter of March 15, under the Freedom of

Information Act. Also provided was an Agenda, a draft copy of the Charge, Structure and Guidelines for the P&A Advisory Council for Mental Health Advocacy Services, as well as an overview of the complaints and problems identified to date by the Patient Advocate who has been employed at Delaware State Hospital.

15. This was more information than had ever been made available to us before as members of the Advisory Board. In the meeting itself was distributed a brief excerpt from the Accreditation Manual for Hospitals and a Legal Needs Survey from the Community Legal Aid Society, Inc. This was a wonderful change in attitude and behavior and marks the first time there was an open sharing of information with the P&A Advisory Board.

16. The Program Director drew everyone's attention to Paragraph 9 of the draft Charge, Structure and Guidelines for behavior of Advisory Board members (see Exhibit 3A) and asked for any additions to strengthen and expand this part of the operating rules of the Advisory Board.

17. As requested by the P&A Director, I furnished copies of my statement made before the House to all members present. The Program Director stated that she did not want to discuss this or any related issue, and would table any further comments because the Director of the Legal Aid Society of Delaware would attend the next Advisory Board meeting and only at that time, in the presence of the Director, would it be appropriate to discuss these issues.

18. It was stated that instead of moving the Advisory Board meeting to a quarterly schedule as had been previously suggested by the Program Director, the Advisory Board would now be scheduled to meet every month.

19. At this meeting I asked for information on the expenditure

of funds for the P&A program thus far in Delaware and a statement if only in very general terms of the total budget for the Legal Aid Society of Delaware. The Program Director stated that she would not furnish this information and explained that, in an article appearing in The Stigma, a newsletter of the consumer movement in Delaware, there had been several "misrepresentations" and on that basis she would supply no fiscal information to the Advisory Board.

20. On Tuesday, April 26, a meeting of almost all of the leadership of the mental health consumer movement in Delaware was called by the Director of the Mental Health Association of Delaware and arranged by Mr. Craig Stevens, the Patient Advocate. I could not remain for this entire meeting due to a scheduled court appearance. At the meeting an excerpt of material extracted from the testimony prsented before the House was presented (see Exhibit 4, Mental Health Report, April 28, 1988, p.75) and was distributed after I had excused myself. In conversations with consumers who were present I understand that they were urged to exercise control and restraint over me personally. Although three of the six consumers present had been given by me a copy of my presentation made to the House subcommittee, there was no question raised by either the leadership of the Mental Health Association or the Patient Advocate as to whether or not that material was correct or relevant in the opinion of any mental health consumers present.

21. I personally feel that since my presentation to the House on April 25 there has been a profound reaction in Delaware to my testimony. I would hope that after the immediate defensiveness subsides, those responsible will be able to hear that I am not here to be critical of what has been done in the P&A Program thus far in Delaware. My point and

reason for submitting this statement today is just the opposite. In fact, when I testified in front of the House I testified that I had not been able to get any information about the P&A Program in spite of serving as a member of the P&A Advisory Board. I am submitting this statement today because I believe firmly that the P&A Program is the greatest breath of fresh air to blow into the labyrinthian catacombs of the mental health system and I want its voice strengthened and amplified by the voice of mental health consumers all across our nation. The obvious way to do this is to strengthen the P&A legislation and that is why I am here today. I feel that mandating cooperation between the Advisory and the Governing Boards will accomplish that end.

22. I want also to note that after hearing the testimony of other consumers at the House Hearing, I was so moved that I wrote to the Legal Aid Society, the Delaware P&A agency, to urge them to consider employment of consumers as a matter of affirmative action (see letter dated May 3, 1988, attached as Exhibit 5).

23. I hope and pray that what I am doing is correct. I know that I am speaking the truth when I say that it is not whether the P&A program is doing OK that should be the issue, but whether it must be strengthened and made to grow. That is the real issue. I am not calling anyone to task, or even responding to accusations made against the consumer testimony by vengefully accusing someone else of lying. I am working to strengthen and support a P&A movement that is working well in many areas, and as I testified before the House, is even making great strides in Delaware, where our mental health conditions are especially deplorable. What I want, and what all of us in this movement want, is a stronger P&A program with more room and more light and more consumer and

family voices speaking out, which will cause it to further grow and prosper. I hope my voice will become a part of a swelling chorus of responsive consumer empowerment across our country.

24. As you can see from my statement today, my coming to a national forum with this issue has already made a difference in Delaware. The Governing Board and the Program Director in Delaware are for the time being "highly" responsive and interacting with the Advisory Board and consumer issues. Will this example support the efforts of other mental health consumers? Will you see that this is the direction that all states begin to move toward?

Thank you for your attention.

Sworn and Subscribed
before me this ____
day of May, 1988.

Signed: ______________________
Quinn Rossander

APPENDIX B

Affidavit of
Laura Van Tosh
Director
Outreach, Advocacy and Training Services (OATS)
311 S. Juniper Street, Room 902
Philadelphia, PA 19107
215-735-6367

for submission to the
House Health and Environment Subcommittee
Protection and Advocacy for Mentally Ill Individuals Act
Reauthorization Hearing
April 25, 1988

I, the undersigned, being of full age, do hereby depose and swear as follows:

1. I am currently Director of Outreach, Advocacy and Training Services (OATS), a consumer-run project for mentally ill homeless individuals in Philadelphia.

2. Prior to coming to Philadelphia in April 1987, I lived in Washington State, where I have been institutionalized. I have also been involved in housing and rehabilitation programs. I am a former member of the Washington Advocates for the Mentally Ill (W/AMI) board and have chaired two committees. I have participated in the surveys of King County residential and community mental health center programs. I am founder of the W/AMI consumer group. I am a former member of the National Alliance for the Mentally Ill Client Council, representing Washington State, and a National Mental Health Consumers' Association representative. I have participated on numerous panels, workshops and conferences on behalf of W/AMI.

3. In 1986, I was selected to be a member of the Washington State Protection & Advocacy (P&A) Advisory Board as a primary consumer of mental health services. My selection was determined by the Executive Director of the P&A agency in Seattle, Washington. The final appointment

was made by the already-existing Governing Board, whom I had never met.

4. At that time, I was an active board member of Washington Advocates for the Mentally Ill. I was also very familiar with the P&A legislation and the responsibilities of the Advisory and Governing Boards, the purpose of the P&A, and the role of subcontracting with regard to the possibility of the P&A's contracting with outside agencies or programs.

5. During the interview process for the P&A Advisory Board, the Executive Director asked me if my involvement with W/AMI would affect my position on the Advisory Board, in terms of conflict of interest. The Executive Director told me that he had "heard" things about the W/AMI leadership and therefore was concerned about my participation on the P&A Advisory Board. However, my skills and knowledge of the system prevailed and I was ready "to work." I was very interested in the opportunities for consumers in Washington State as they pertained to the P&A and affiliate activities.

6. During my period of involvement in W/AMI, the W/AMI organization had accomplished many of the P&A-type activities and I had wondered why their involvement with the newly created P&A office could not be possible. In fact, my W/AMI involvement was seen by the P&A Executive Director as threatening. It appeared that my position on the W/AMI board was something that affected my involvement as a consumer on the P&A board.

7. During the several months following my appointment the Advisory Board never met. I did not even know who else was on the board. The Executive Director was not forthcoming with information about the board membership and was rarely, if ever, available by phone. Although this was frustrating, I knew that the new Executive Director was busy setting up "shop." The Executive Director told me that he had never worked or resided in Washington State prior to his appointment as such.

After many communication attempts, I spoke with him. His "plan" for the Washington State P&A was to place two lawyers in the major state hospital facilities to find cases. Having read the law, I was concerned that this "plan" was to be put in place with no input from the Advisory Board. Additionally, I was concerned that this was a misuse of funds and that a more cost-efficient plan could have been organized, for example, by establishing consumer and/or family groups. There was absolutely no room for input or opportunities for consumer involvement in the decision-making or alternate programming.

8. The National Association of Protection and Advocacy Systems (NAPAS) and NIMH conference on the P&A law was going to be held in St. Louis, Missouri, in January 1987. I had learned about this through the National Mental Health Consumers' Association. I struggled for consumer involvement at this conference as an attendee from Washington State. After some effort on my part, The Executive Director was finally convinced that family and consumer representation at this P&A national technical assistance meeting was vital.

9. Throughout the months to follow, I had requested the P&A Executive Director to provide more information on the role of the Advisory Board. He was unresponsive and continued to fail to arrange meetings of the Board.

10. Upon learning that I was going to move from Washington State in April 1987, I wrote the Executive Director to resign from the Advisory Board. I included several recommendations for a consumer replacement. It was months before a consumer replacement was selected by the Executive Director. I am not only concerned about consumer involvement of the P&A from the standpoint of representation of consumers, but whether this is directly affecting the services the P&A is supposed to provide. I have

only just recently been informed that consumers are finally represented on the Advisory Board and that, more specifically, the Board is actually meeting.

11. In February 1988 I visited Washington State and spoke again with the P&A Executive Director. He continued to express ambivalence in the areas of subcontracting with families or consumers to perform the much-needed P&A services in Washington State.

12. As I have said before, two P&A lawyers are working in each of the two state institutions in the State. I have learned that they each are focusing on environmental issues with the state hospitals, such as covering exposed pipes from which people are hanging themselves and Union/staff relations in terms of cooperation with the P&A lawyer. Again, these issues are not directly affecting the rights/lives of most patients in these hospitals.

13. Neglect and abuse of consumers is occurring all over Washington State: in community residences, in the discharge planning of inpatients, and within the wards themselves. The P&A lawyers are handling issues that are not appropriate for the purposes of the P&A. The reflection of the Advisory Board's composition and lateness in involving consumers is evident in the focus of their principal P&A activities. From the perspective of truly protecting and advocating for consumers, it would be hard not to question the Washington State P&A policies and priorities developed without adequate consumer and family input.

14. With Washington State receiving a minimum allotment, I found the use of the funds to be costly and potentially ineffective. Additionally, no consumers have been hired by the P&A for the mentally ill

in Washington State. The achievement of the P&A's goals of protecting and advocating for consumers have been frustrated by the P&A's failure to involve consumers and family groups in its policy, priority and program development.

Sworn and Subscribed
before me this [illegible]
day of April, 1988.

Laura Van Tosh

BRENDA JEAN CRAWFORD
Notary Public, Phila., Phila. Co.
My Commission Expires Dec. 12, 1988

APPENDIX C

Volume 5 Number 1

Winter 1988

Portland Coalition Advocate

Newsmagazine of the Psychiatrically Labeled

Welcome Associates!

With the start of a new year, the Portland Coalition has launched an exciting new program to include community people in our organization. The Portland Coalition Associates program is open to all persons who would like to support the work that we are doing, but who do not qualify for PCPL membership or do not choose to identify themselves as "psychiatrically labeled." Associates may select one or more options:

- **Community Associates** will support the PCPL through their dues and other contributions.
- **Maitri Associates** will seek to form supportive friendships with PCPL members and other mental health clients in the community, nursing or boarding homes, schools, and elsewhere. (*Maitri* is a Sanskrit word meaning "loving kindness" or "friendship.")
- **Technical Associates** will offer technical support in areas such as fundraising, grantwriting, administration, furnishings, legal matters, etc.
- **Advisory Board Members** will support and advise the PCPL Board. The two boards will share members as liaisons and will sometimes work together through joint committees.

Portland Coalition Associates already include many persons who have given us support over the years, such as Neva Cram from Ingraham Volunteers. New Associates include Eleanor Steele, who seeks to pursue new areas of public education and support with children and the children of psychiatrically labeled persons. [See *To My Mother* on page 3.] As the program got under way this January, over 50 persons had already signed up as Associates.

All Associates are asked to pay dues of $25 a year, with additional donations requested from those able to provide such support. For more information write to Portland Coalition Associates, P.O. Box 4138, Station A, Portland, Maine 04101, or call 772-2208.

Don't compromise yourself. You are all you've got. – Janis Joplin

PCPL TELLS BUREAUCRATS, "KEEP YOUR $50,000"

In December the Portland Coalition shocked the feds and the rest of the mental health system by declining a second year's funding from the federal protection and advocacy (P&A) system. Up to $50,000 was approved by the Advocates for the Developmentally Disabled (ADD). But the PCPL board of directors voted to refuse it, and director Dianne Côté told ADD to keep their money.

Are we crazy?

The PCPL's decision came after over a year of what might be called abuse and neglect by ADD, the Maine agency that is supposed to conduct P&A for the rights of mentally ill persons. Our problems began last fall when we asked ADD for assistance in administrative issues and in meeting federal requirements for our new grant. These requests were denied outright. ADD's director did ask the Bureau of Mental health to help us find an accountant to get our books in order. But it turned out that the person that the BMH recommended was unable to handle the complexity of our budget, and this set the stage for further conflict with ADD.

Meanwhile, our staff worked diligently to deliver the comprehensive advocacy program that we had promised in our contract. For eight months we successfully advocated for patients at Maine Medical Center, AMHI, and elsewhere, and we represented psychiatrically labeled persons statewide through systems advocacy in state agencies and the legislature. We more than lived up to our promise, but ADD did not seem to notice. Not once during the entire year did ADD's director or board discuss with us the actual work we were doing, and the P&A Committee set up to review the program seemed unwilling either to evaluate or commend our work.

In December 1986 ADD announced that the PCPL must move to a handicapped accessible office within three months or else lose all P&A funding. In January the agency withheld funds until we complied. The PCPL had in fact already been looking for accessible office space for nearly two years, and had reluctantly moved to the Valley Street office only because several Portland landlords refused to rent their accessible facilities to ex-mental patients.

continued on page 2

SPECIAL EDITION

This edition of the *Advocate* is published in a much shortened form, and "hand set" on Sally's computer, due to lack of funds

Is Governor McKernan Selling Us Out?

The Portland Coalition has recently learned that nearly 30 acres of land belonging to the Bureau of Mental Health have been released for sale and that the Maine legislature will be asked to allocate these funds in February to the Governor's emergency fund.

The largest portion of land to be sold is 25 acres next to BMHI, with another 4 acres adjacent to AMHI. Also to be sold is a brick building valued at $400,000 at 3 St John St. in Portland. Our sources tell us that total proceeds will amount to over 4 million dollars.

Selling the property that currently belongs to the Bureau of Mental could enormously benefit the over 8,000 clients of the state's mental health system. It could buy some much needed community mental health facilities, as well as several residences and shelters for mental health clients. By our calculations, the money could buy 100 Office Managers for the Portland Coalition *plus* 495 years worth of newsletters. Our organization now receives only 2500 dollars a year from the state.

But mental health clients may benefit very little from this transaction, for only a small portion of the emergency fund is earmarked for mental health. The rest goes for such items as workers' compensation for

continued on page 2

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Selling Out *continued*

state employees and other general costs–including, we hear, potholes

The Portland Coalition is currently talking with other advocates and consumers in the mental health community We hope to establish a coalition with the goal of directing funds from the sale of Mental Health Bureau property back to mental health services where they belong

Bureaucrats *continued*

When ADD gave their ultimatum, Dianne Côte explained the difficulties we had experienced and again asked for legal help in dealing with discrimination and accessibility issues Again ADD refused. As a result, pressure was placed on the already overloaded shoulders of the PCPL advocates, who had to continue their P&A work while at the same time combing Portland for an office that would be accessible, affordable, and open to the psychiatrically labeled

Eventually we found a new office, but at a heartbreaking cost The unavoidable frustrations involved in direct advocacy and the stress of our sudden growth with its administrative complexities—all compounded by ADD's neglect and our anxious search for accessible quarters—were beginning to take their toll on the PCPL staff It began to be clear that bookkeeping matters were going downhill; nevertheless, and without any guidance from ADD, the PCPL staff struggled to maintain the quality of our advocacy We did keep that quality, but still ADD did not notice.

In the spring the PCPL books still had not been brought up to date, and ADD withheld our third quarter payment of $18,000. Thus began over eight months of agonizing financial reviews, adjustments, and negotiations among ADD, PCPL accountants, and PCPL staff The financial situation became a comedy of errors in which the PCPL staff spent hours working with our own accountants, more hours defending our reports and budgets to ADD staff, and still more hours revising our figures in an attempt to meet ADD's demands. In early June we moved to our new office and paid $3000 to make the bathrooms accessible, and we finally received the $18,000 withheld in April.

It was too late. Immediately afterwards every single one of our five staff members burnt out. Two of us took an extended leave of absence, two advocates quit, and one broke under the pressure and had to be hospitalized. This event was extremely painful both to the PCPL staff who left and to those of us who remained, and these wounds will take a very long time to heal.

By this point our relationship with ADD was strictly adversarial. ADD itself was undergoing a change in leadership, and we were left at the mercy of their accounting department In July Dianne dismissed our first accountant–the one who had been recommended by the BMH—and again asked the Bureau for help Although ADD had paid us for April, they were now questioning our next report and would not send our fourth quarter payment. In response the BMH assigned one of their people to bring our books up to date. Nevertheless, four more months elapsed before this was done, and it finally happened only when the PCPL brought in yet a third accountant with the help of Diocesan Human Relations.

We now recognized that a program of advocacy as ambitious as ours required thorough advance planning and administrative reorganization. We had proved ourselves to be capable advocates, but we had neglected to develop the managerial foundation necessary to carry out such work and to satisfy the bureaucracy. In July, after months of working overtime and almost singlehandedly to get all the work done, Dianne asked the BMH to fund an Office Mananager to relieve her This request was refused, and in the absence of financial help from the BMH, Dianne continued to be embroiled in ADD's bureaucratic demands as well as dealing with all administrative work, advocacy, and public education.

By the end of the year the PCPL had received only $5,000 of the fourth quarter payment of $18,000 that had been due since July. ADD continued to pick apart our yearend report piece by piece, and they eventually agreed to pay us only a portion of the full amount contracted. This final, and still incomplete, payment did not arrive until January.

Although the ADD board finally approved a second year contract with the PCPL for up to $50,000, it had taken Dianne and Sally nearly four months to negotiate the contract. These were four months of grueling days creating and revising budgets, writing proposals, designing work sheets, and doing other bureaucratic activities that are an inevitable part of getting grants. Just getting the new P&A contract had cost too much in human terms, not just to those who fought for its approval but also to all the other PCPL members who would not really benefit from the kind of work that ADD required, with all its hassles. That is why we turned it down

We are told, and I have no doubt that it is true, that entire careers are based on manipulating bureaucratic grant money All of these activities seem to be exponentially increased for federal funding, and especially in this case with the developmental disability system's fundamental ignorance of the needs of mental health clients. It is appalling, but true, that in a bureaucracy the love of money is the bottom line, and good works are just ink on paper

Economic Stress

The obvious flow of bills and and silver
Accumulates in a noise of payments
  that obscures
The larger economic torrent
  that changes weather
In its longer streams
The price of prodigality is
  the inflation of hunger
And the diminution of worth.

Ten million ballpoint pens will
  not write letters
Of praise and comfort,
  and fifty million clips
Will not fasten the broken strings
Of unstrung lives.

Time itself is a stream stocked
  with numerals,
And the pollution of its figures
Stops up oceans.

— *Sally Clay*

The Ball

I remember when the ball
hit me hard in the stomach
I could neither breathe
nor talk to tell them
I couldn't breathe.
But they knew
I could tell they knew
by their faces.
They stood and waited—for the ball.
I stood and waited for breath
I decided then, which was more
important to them.
I wasn't afraid,
because I was always afraid

— *Lowry Geary*

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APPENDIX D

Affidavit
of
William J. Butler
Steering Committee Chairperson
Coalition of Mental Health Consumers Organization
906 Grand Avenue
Asbury Park, NJ 07712
201-776-7722

for submission to the
Senate Committee on Labor and Human Resources
Subcommittee on the Handicapped
Protection and Advocacy for Mentally Ill Individuals Act
Reauthorization Hearing
430 Dirksen Building
May 10, 1988

1. I, the undersigned, William J. Butler, 115 Asbury Avenue, Ocean Grove, NJ 07756, being of full age, do swear and affirm the following:

2. I am a member of the Protection and Advocacy Board of the state of New Jersey. I am a primary consumer (ex-mental patient), hospitalized for over four years of my life. In New Jersey, the P&A Board is controlled by the New Jersey Department of the Public Advocate, the Division of Mental Health Advocacy.

3. As Board members and primary consumers, it has been our mission to focus on the deaths of patients at state institutions. Exhibit 1 -- New Jersey Consumer Operated Self Help & Advocacy Program (NJ COSHAP) Newsletter, Volume 3, No. 1, Page 7 -- itemizes consumer wishes to be placed on clinical and disciplinary Review Boards. Expressed at P&A meetings, this wish has not been acted upon.

4. Exhibit 2, consisting of the April 10, 1988 edition of the Asbury Park Press, p. A-1, article by Frank Argote-Freyre, "Details still awaited in death of psychiatric patients," depicts the ongoing inefficiency of the Public Advocate to solve several cases. Most patient death cases are unsolved.

5. Exhibit 3, Id., at p. A-4, "Investigations into Patient Deaths at State Psychiatric Hospitals," again compiled by Mr. Argote-Freyre, shows that eight of the 13 cases are still under investigation by the Public Advocate, the oldest dating back to December 19, 1986.

6. Exhibit 4, Id., "11 months later, a family still waits," depicts the personal tragedy of Joan Marie Tapke, dead at 27 from "cerebral and pulmonary edema." Brain and lung swelling caused by multiple drug ingestion are said to be the cause.

7. -- But we still don't know. Whether at 38, 27 or 14, the tragedies are unanswered. Through a printed page, we have the chance to look at the faces of these young people. I cannot bring back the life of a 14-year-old boy, yet I find it within me to stop the tragic death of another young person. Protection and Advocacy provides the key -- not only to stop abuse and neglect, but death itself.

8. After my testimony before the House Subcommittee, on April 25, 1988, another article was printed in the Asbury Park Press, (April 26, 1988, "Advocate targets psychiatric hospitals," attached as Exhibit 5). Despite all of this publicity and concern, the Public Advocate -- our P&A -- has not yet resolved the concerns of consumer and families.

Sworn and Subscribed
before me this ______
day of May, 1988.

Signed: ________________________
William Joseph Butler

APPENDIX F

6008 Virbet Drive
Cincinnati, OH 45230
April 11, 1988

Joseph A. Rogers
President
National Mental Health Conumers' Association
311 S. Juniper Street, Room 902
Philadelphia, PA 19107

Dear Joe:

In response to your request for information about P&A Advisory Boards, I am enclosing a memo by Ohio P&A Director Carolyn S. Knight unilaterally canceling our latest meeting, and a letter which I wrote Ms. Knight. (I apologize for the uncorrected carbon copy of my letter, which is all I still have in my possession.) My letter was sugar coated even on March 22, and now I am even more angry and frustrated, for Ms. Knight has not followed through on the promises in her memo. We have not been contacted to reschedule the meeting, and have received no information about Am. Sub. S.B. 156. Of course, I have received no response to my letter to Ms. Knight.

I totally support your efforts in the P&A reauthorization. I doubt that the Ohio Advisory Board will ever have a real impact without explicit legislative language stating that it has some real power.

Sincerely,

Fred

Fred Zimmerman

cc: Tracey Bennett, Advisory Board member

Ohio Legal Rights Service
[illegible]

TO: Mental Health Protection & Advocacy Committee Members

FROM: Carolyn S. Knight, Executive Director CK

RE: March 26th Committee Meeting

DATE: March 18, 1988

Because of unforeseen conflicts on the part of OLRS staff, particularly myself, it has become necessary to postpone the Committee meeting scheduled for March 26. Kathryn (Casey) Council will be contacting you by telephone to reschedule the meeting. We are tentatively looking at the dates of April 16 or April 23rd depending on Committee members' schedules.

Actually, this meeting change will probably allow us to have better organized our information concerning Am. Sub. S.B. 156 which as most of you probably know by now, has passed the General Assembly and is awaiting the signature of Governor Celeste. As is usually the case in legislative matters, after months of no real movement, the bill moved incredibly quickly in two weeks time. We are in the process of putting information about the Bill together and we will hopefully be able to get a mailing out to you for discussion purposes at the next meeting. In the meantime, if you have questions regarding the Bill, please contact Tim Tobin or Becky Hess.

One last note, if anyone believes they may be unable to attend the Committee meeting because they cannot "front" the travel expense involved, i.e. busfare, gasoline, etc. please mention that fact to Casey when she calls you. I can't promise that I can force the state system to bend to meet your needs, but I can certainly promise to give it my best effort.

We hope to see you in April!

6008 Virbet Drive
Cincinnati, OH 45230
March 22, 1988

Carolyn S. Knight
Executive Director
Ohio Legal Rights Service
8 East Long Street, 5th Floor
Columbus, OH 43266-05232

Dear Carolyn:

I am writing to express my concerns about consumer involvement at OLRS.

I have been very favorably impressed with the very competent and dedicated staff members I have gotten to know in my work with the Advisory Committee. It is clear that OLRS is deeply committed to representing consumers' wishes in individual case advocacy and generally does an excellent job within its budgetary limitations. However, I feel that OLRS needs to do a better job in mobilizing consumers to participate in making the systemic changes needed to make the mental health system reflect the needs and desires of its supposed beneficiaries.

The Advisory Board could be one vehicle for mobilizing consumers. Our lobbying on the Mental Health Financing Plan is one example of the way consumers can attempt to have an impact on the system. But I wish that the Committee had been established several months earlier, and I think that an earlier start would have given us a chance to make more of an impact. I realize that early 1987 was a particularly busy time for OLRS, with its expansion and employee unionization.

I spent many hours of unpaid work involved with the Advisory Committee response to the Mental Health Financing Plan and was happy to do it. I was grateful for the support and assistance of OLRS staff. But when the bill started moving quickly, I was unable to obtain any information from OLRS.

I have been working to get one potential Committee member and another person iterested in the Committee. It is somewhat embarassing to find the March 26 meeting postponed with one week's notice without consumer involvement in this decision. Of course the Commttee's internal procedures have not been defined, and we need to do this at the next meeting.

Page 2

I hope that OLRS will actively compete with the Ohio Department of Mental Health for consumer support. On the National Consumer/Ex-Patient Teleconference, there has been shock and dismay, even from "moderates" at the ultra-conservative and co-opted nature of the ODMH-controlled Ohio consumer movement. There is no reason to believe that Ohio consumers are especially conservative, and I suspect that ODMH has won many consumers' allegiance by default. Consumers could be extremely powerful in advancing the OLRS philosophy of rights and empowerment in the legislature and the community. I look forward to working with you on our many common concerns.

Sincerely,

Fred Zimmerman

APPENDIX G

15 April 1988

Joe Rogers, President
National Mental Health Consumers' Association
311 South Juniper St. rm 902
Philadelphia, Penn.

Dear Joe:

I am enclosing with this letter an affidavit of the situation which pertains to the Protection and Advocacy Service of Michigan. Because you are the spokesman of the major organization of primary mental health consumers, I ask your assistance in placing this information before the Congressmen so that the defects of the law authorizing and directing the provision of protection and advocacy services for the mentally labeled may be made more useful.

The promise of the protection of the rights of the mentally labeled has not been fullfilled in Michigan. And, clearly, the reason has been that the primary consumers have not been allowed their legal and rightful share of the responsibility for the operation of the P & A services.

I urge that you continue to work for the correction of the abuses against the mentally labeled as you have so ably done in the past. I stand ready to support you in this work to the utmost of my ability. All my experience in this work shows that if any improvement is to be made in the situation of the mentally labeled then they, themselves, must be allowed the opportunity to make it work.

I give thanks to G-d for your efforts in our behalf and pray for your continued good health.

Sincerely,
Bernie Elbinger

Bernie Elbinger
Michigan Alliance for Psychiatric Alternatives
10574 Park Terrace
Detroit, MI. 48204
313/931-7308

AFFIDAVIT

I, Bernie Elbinger, do affirm the following to be true to my knowledge and belief.

I am 61 years old and have lived in Detroit. Mich. most of my life. I was involuntarily committed in 1962 and from 1966 to 1969. I lived in Israel from 1970 till 1977 in order to regain my mental and physical health. I returned to this area in 1977. Before my mental incarcerations I operated my own electrical contracting business. Since my disablement by the so-called "treatment", I am unable to work at my former trade.

I have been involved with the mental consumer movement since I returned from Israel in 1977. I was active in the establishment of the Michigan Protection and Advocacy Service for the Mentally Labeled from its beginning in 1985 and I served on its first Services Development Board (SDB). I also served on the Citizen's Advisory Council of the Northville Regional Psychiatric hospital from 1983 to 1987. I am convinced, by my experience on these boards and councils, that the decision making for the mental health consumers must be done by the primary consumers themselves.

This idea was supported by Dr. Margolus, from the Michigan Psychiatric Society, on a TV program together with the Dept. Director and several consumers. The doctor agreed that the system offers too few opportunities for decision making by the consumers. The Mich. P & A Service has done nothing to correct this abuse.

In the beginning, we, the major group of active mentally labeled persons in Mich., the Psychiatric Alternatives Alliance (PAA), favored the contract with the P & A Service for the D.Ds. However, once the contract for P & A Service to the mentally labeled was signed, their attitude of helpfulness ended.

The SDB of the P & A Service was not to be a mere advisory board. This is shown by its name. A decision that 75% of the members were to be primary consumers was agreed to by all the persons concerned. The definition of two classes of consumers was done to clearly differentiate between the primary consumers. those with direct hospital experience, and the secondary consumers, the family and friends of the primary consumers. It is recognized that the interests of these two groups do not always coincide and the interest of the primary consumer is to be paramount. However, once the Service got its contract its promise to the primary consumers dissolved into bureaucratic double-talk. This was a "betrayal" of our mandate to the Service. Staff, inexperienced with the mentally labeled, were hired without regard to a resolution passed by the SDB that primary consumers were to be given preference.

When an accounting for failures by the service was demanded, the SDB was dismissed by the executive board of the parent organization citing the P & A law as the excuse. Letters from the P & A officers show the SDB was the victim of a secret plan, "Phase one". The result is that the new, hand packed, board is not effective. It cannot attract a quorum to its meetings. It is not trusted.

Substantial matters of abuse and violation of rights are not addressed. The P & A Service has not provided a method of direct communication with the inmates confined on the wards. Its toll-free 800 number is not assessable by the telephones on the wards. This is a violation of the Mich. Mental Health Code.. 330.1726. This was brought to the attention of the executive director countless times but to no avail. The P & A Service office which was located on the grounds at the Northville facility has moved and no one seems to know or care to where.

I am convinced that the death of inmate Edgel McMahen was caused by the lack of protection from the P & A Service. They ignored his request for legal assistance when he was faced with a Show Cause Order for his release. The mental strain and overmedication caused him a life-threatening epileptic attack. Although he was 6'5" tall, he weighed 112 # at his death several months later. The P & A Service did absolutly nothing to assist him despite repeated calls by me.

When the director of the Northville facility arbitrarily canceled Friday night Jewish services. the P & A service actually was obstructionist in advocating for a permanent solution to this violation of rights. This violation was corrected, – with no help from the P & A Service –, when I, acting through the Jewish community, brought the matter to the attention of the Governor's office. In a letter to the facility Director the P & A Director of the Mentally Labeled division found no cause for concern. That deprivation of religious service has caused a mental digression of an inmate for almost two years. Thus, the Jews suffered deprivation of a 1st Amend. right while the two Directors were satisfied that all was well. Clearly the trouble in this matter was that the P & A Service acted for itself, as the principal, and not as the agent. for the consumer. This defect seems to be common with the professional mental health workers. Thus, the lack of progress towards independence of the consumer.

Although I am at the Northville facility each week as an assistant to the Rabbi, I am unaware of any program or project for the mentally labeled at that facility which was promised before the service got its contract. And while it had an office at the facility it seems that their main concern was with harassing the Office of Recipient Rights of the Dept of Mental Health. They push their own agenda.

The selection of the evaluator of the service is biased. He is a professional member of the same professional advocacy organization with the Service Director, Mrs Bower. The bias of the professionals that protection and advocacy is like any other therapy which only the professionals can give to the "mentally ill" is apparent from their unwillingness to accept the primary consumer into their own decision making process. The evaluator witnessed the walk out, literally, of the SDB in protest because of the "betrayal" of the service yet, he did nothing effective. The professionals protect professionals.

The Service did move its office in Lansing closer to the Capital Building. This may be fine for the professional bureaucrats but it makes access for the consumers extra difficult and costly.

Many of the staff assigned to the Mentally labeled division of the service had no experience with the special problems of the mentally labeled consumer. One dedicated staffer was driven from the Service. A former consumer and also a professional. who was hired by the Service admitted to me he violated his own integrity in order to vote against me and his own proposal because I supported it. The Rabbi witnessed him admit to an abuse against me in violation of Mich. law. This same person told me he thinks our society "raped" him. The few consumers who remain with the Service have a dependent or "leftist" bias.

In short, the Michigan Protection and Advocacy Service has done more to promote its own welfare and that of the professional bureaucrats than the welfare of the mentally labeled. Its sponsorship of the 1987 NARPA conference in Detroit is a case in point. Because of lack of support and betrayal by the P & A Service our PAA organization has dissolved. Thus, the effect of the Mich. P. & A Service has been very negative. The pattern of abuse, violation of law, lack of integrity, and bureaucratic bungling will end only when the primary consumer is given an opportunity to take charge of his own welfare and interests. No one can have a better interest in a property than the owner.

Bernie Elbinger ______________________ date 16 April 1988

Bernie Elbinger

Subscribed and sworn to before me, a Notary Public, this 16TH day of April, 1988.

Notary Public, Wayne County, MI
My Commission Expires Mar. 16, 1992

My commission expires MARCH 16, 1992

page 2 of 2 pages

APPENDIX H

March 28, 1988

COALITION RECOMMENDATIONS FOR REAUTHORIZATION OF PL 99-319

(PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS)

This document, endorsed by a coalition of mental health organizations active in advocacy on behalf of people labeled mentally ill, recommends that Congress reauthorize the Protection and Advocacy for Mentally Ill Individuals Act for three additional years with few major changes in structure, authority or operation. The program's continuation as currently constituted, but with substantially increased funding, is necessary for the orderly development of assistance to mentally ill people in residential settings.

Although PL 99-319 was authorized for three fiscal years, 1986 through 1988, the first fiscal year saw no activity. The Act was passed in May and grant awards were issued in September. As of March 1, 1988, therefore, the program has been operational for seventeen months. A full assessment of the program must await more operational experience.

However, based on information received from Protection and Advocacy Systems as well as other advocacy groups, we recommend modifications in several areas where specific issues have been identified in a sufficient number of states to warrant legislative attention. These include:

- composition of the governing authority of the PAMIs;
- role of advisory boards in developing policies and priorities;
- PAMI access to facilities and records;
- expanded eligibility for PAMI services;
- client grievance procedure and public comment on system's annual policies and activities;
- minor changes in administrative procedures;
- authorization levels.

1. Composition of the governing authority

Although a significant number of P&As have added representatives of the mental health community to their governing boards, many states still have agencies whose boards lack members knowledgeable about the special advocacy needs of people with mental illness. Since board members are often appointed for multi-year terms, an immediate change in composition is not practical.

The coalition recommends the follow addition to Section 105, System Requirements:

"( ) establish a governing authority

(a) by October 1, 1990, for systems organized as private non-profit entities or public systems with multiple-member governing authorities, is broadly representative of the clients served by the system;

(b) approves the annual statement of priorities developed jointly with the advisory board; and (*)

(c) selects its members according to its own policies and procedures, except that, for private non-profit organizations, the chair of the advisory board shall be a member of the governing authority."

The coalition understands and intends the word "approves" in ( ) (b) above to mean that the governing authority may accept or reject priorities jointly planned with the advisory board, but may not modify them or substitute policies and priorities at variance with those presented for its approval. It further understands and intends that the "approval" authority granted under this subsection would permit a governing body to reject a portion of the jointly planned priorities and implement the balance. In the event jointly planned priorities are rejected in full or in part, those rejected elements could be reviewed and revised through the joint planning process and resubmitted for approval. The joint planning process, as envisioned under this subsection, is flexible to the extent the planning activity could be done through a joint sub-committee or by delegation to the advisory board alone, or through other mutually agreeable arrangements which retain the essential features of involvement of the advisory board in the process and a requirement for advisory board consent to the priorities advanced to the governing authority for approval.

2. Role of the Advisory Board to a PAMI

Under current law, each PAMI must have an advisory board to "advise the system on policies and priorities...." Member groups of the coalition have received reports that in some states the recommendations of advisory boards have been ignored because the boards had no real connection with the actual decision making-process in the agency, i.e. the governing authority. (NAMI will supply examples.)

The coalition recommends the following change in the current advisory board language designed to promote greater advisory board involvement in the priority setting process. (additional wording underlined; deleted words in parentheses):

"(6) establish an advisory board

(a) which will develop, jointly with the governing authority, an annual statement of (policies and) priorities to be carried out in protecting and advocating the rights of mentally ill individuals; and...." (*)

The change will require the governing authority to fully engage the advisory board in developing the agencies policies and priorities. The final approval of the policies and priorities, however, would remain with the governing authority.

3. Access to Facilities and Records

Access to facilities, residents and their records is essential to PAMIs fully serving the needs of their clients. Many PAMIs have been able to obtain state legislation authorizing needed access or negotiated agreements with state officials. PAMIs in several states, however, are reporting resistance to full access to facilities and barriers to needed client information. A few PAMIs have reported that prior appropriate access disintegrates when the PAMI files litigation or engages in other aggressive advocacy activity. Other complaints include refusal to allow access to records of a deceased resident or one whose whereabouts is unknown. (See endnote 1 on p. 7, infra).

The coalition recommends the following changes to strengthen the access provisions in the statute: (new language underlined)

"Section 105 (a)(4)(B)...

(i) who by reason of the mental or physical condition of such individual (including individuals who have died or whose whereabouts are unknown) is unable to authorize the system to have such access."

Two other concerns raised by PAMIs involve the need to assist a resident with the transition from institution to community and information on incidents involving residents which occur in the facility. Since eligibility for advocacy services continues 90 days following discharge from the facility, it is important for the PAMI to be aware of post-discharge arrangements, including application for various Federal and state benefits, coordination with community mental health providers and appropriate housing.

The coalition recommends amending Section 105(a) to add a new number (5) and renumber existing paragraph 5 through 7 accordingly:

"(5) have access to discharge planning sessions conducted in the facility and access to reports of incidents of abuse and neglect prepared by the facility staff and to attend meetings which review such reports."

4. Expanded Eligibility for PAMI Services

a. Coverage of Federal facilities

PAMIs have received requests for services from Veterans Administration hospitals, Department of Justice prisons, Immigration and Naturalization Service facilities. The NIMH Office of General Counsel contends that Federal facilities are not within the scope of the PAMIs' authority. (copy of opinion attached). Congressman Henry Waxman has formally advised NIMH of Congress' intent to cover Federal facilities. (letter attached). Finally, P&As have a ten year history under the DD Act of representing persons with developmental disabilities in Department of Defense schools.

The coalition recommends adding language clarifying that "facility rendering care or treatment" (Sec 102) includes all such facilities owned and/or operated by the federal government. The statement of managers in the conference agremeent on 99-319 said (p.15) "The intent of the legislation is to focus on abuse and neglect of mentally ill individuals and not on the particular residential facility in which they reside. Accordingly, residential facilities could include, but need not be limited to, hospitals, nursing homes, community facilities for mentally ill individuals, and board and care homes." (The statement is repeated almost verbatim on p.16) Congress, through statutory or report language, should expand on this statement emphasizing that the nature of the ownership of the facility is similarly not a factor in determining eligibility for PAMI services. Allotments to PAMIs are available to pay for services to mentlly ill individuals who are residents of private facilities and all levels of publicly owned facilities (federal, state and local).

b. Coverage of state or local jails and prisons

State prisons and particularly local jails have become the dumping ground for mentally ill people who break the law or are accused of law violations (sometimes involving minor infractions which may grow out of their illnesses) and receive little or no care or treatment while jailed. The abuse and neglect of people in these settings, while not comprehensively documented, is well known through wide-spread anecdotal reports.

The legislation does not clearly authorize PAMIs to investigate incidents of abuse and neglect in state and local prisons and jails, particularly the non-forensic units. The coalition recommends the addition of statutory language authorizing PAMI involvement on behalf of individuals diagnosed as mentally ill who are involuntarily in residential settings where care or treatment may not be provided.

c. Coverage of individuals in admissions process

The terms "inpatient or resident" seem to exclude assistance to individuals who are in the process of being admitted to a facility. Frequently, people who are voluntarily entering a residential setting need assistance with matters such as continuation of Federal benefits, maintenance of the family home or child care. Further, individuals who have been picked up by the police and brought to a hospital may have need for legal assistance. The coalition recommends expanding the terms "patient or resident" to include individuals who are in the admissions process, but not to include assistance at commitment hearings.

5. The coalition finds the changes made in the P&A title of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (PL 100-146) wholly salutary and recommends their inclusion in the reauthorization of P.L. 99-319 in Section 105(a):

> "( ) on an annual basis, provide the public with an opportunity to comment on priorities established by, and activities of, the system."

> "( ) establish a grievance procedure for clients or prospective clients of the system to assure that mentally ill individuals have full access to services of the system."

As part of the public comment process, the Committee report should state that the PAMI is to make available its annual budget and report for public examination.

6. Minor changes in administrative procedures

a. Use of volunteers - The coalition believes that PAMIs should be encouraged to increase their use of volunteers, including consumer volunteers, by requiring them to report on the extent to which volunteers provide services (new language underlined).

"105(a)(7)...a report describing the activities, accomplishments and expenditures of the system (including the extent to which the system is utilizing volunteers in the delivery of advocacy services) during the most recently completed fiscal year."

b. 5 percent limit on training - The coalition believes that the limitation of 5 percent on PAMI spending for technical assistance and training (section 104(b)(2)) is counter productive and should be deleted.

c. increase in minimum allotments - The coalition recommends including in the reauthorization the text of Section 301(b)(7) of the DD Assistance Act (PL 100-146). The section provides for increases in minimum allotments when the appropriations increase in any year is greater than the growth in the CPI.

d. annual application and assurances - Unlike the Developmental Disabilities Act and the Rehabilitation Act, P.L. 99-319 requires each PAMI to apply annually for its allotment and for the Governor to provide "assurances" that certain conditions are met. The coalition feels that the requirement is an unnecessary administrative burden and, more importantly, delays grant processing. The application process is redundant since only the P&As can apply. Once the governor has given his assurances, they remain in effect until the governor indicates otherwise. The coalition recommends that the application and assurance process apply only when statutory changes require new or additional assurance or when the governor is planning a redesignation of the agency.

e. sub-contracting - The coalition recommends modifying the language on sub-contracting to provide that the PAMI should consider entering into contracts with self-help groups made up individuals or families of individuals covered under the act. Self help groups have been highly effective in rights education and self-advocacy skills training. While the language would not mandate a contract with such groups, it would enable self-help groups to participate more equally with others in a contracting process.

f. technical assistance - NIMH, the agency responsible for providing technical assistance to the PAMIs, indicates that it has discretion to determine the proportion of total appropriated funds it may use for the purpose. The coalition recommends modifying section 115 to read as follows: (new language underlined)

"Sec.115 The Secretary shall provide technical assistance to eligible systems with respect to activities carried out under this title in accordance with the expressed needs of the eligible systems. No more than two percent of appropriated funds may be used for technical assistance."

7. Authorization levels

It is apparent that even with no changes in the law, the funding levels currently authorized are inadequate to enable PAMIs to fully protect mentally ill people against abuse and neglect in residential settings and advocate on their behalf. The additional responsibilities recommended above make the need for expanded funded even more compelling. The coalition recommends authorization level identical to those authorized for DD P&As in PL 100-146, as follows:

FY 1989	$22,000,000
FY 1990	$24,200,000
FY 1991	$26,620,000

Endnote 1: To supplement Issue 3 on p. 3: The National Association of State Mental Health Program Directors (NASMHPD) has advised NAPAS that we will use our best efforts to informally overcome access problems if we are given a lists of the states where obstacles exist and the nature of the obstacles. So far, we have not received the list. It is NASMHPD's intent that all PAMIs have suitable and appropriate access to state facilities and client records.

Dissents to coalition positions.

* The National Association of Protection and Advocacy Systems (NAPAS) dissents from the coalition position on joint development of policies and priorities between the governing authority and the advisory board. PAMIs have been diligent in establishing and using advisory boards in a manner consistent with both the letter and intent of PL 99-319. Inevitably, some PAMIs will develop smooth working relationships easily and quickly; others will require more than 17 months. However, no foundation has been established for the need to create a complicated and awkward new process for developing policies and priorities. In the absence of information on wide-spread breakdowns in working relationships, Congress should not legislate change, particularly one that mandates an elaborate and untested nation-wide procedure. Further, NAPAS questions the wisdom of Congress legislating a process which may interefere with the legal responsiblities of a PAMI's governing authority. Finally, the process, NAPAS contends, would be completely unacceptable and unworkable in PAMIs which operate under a board of commissioners or other multi-member authority established by state statute.

The National Alliance for the Mentally Ill (NAMI) considers this provision to be essential to the integrity of the consensus recommendations and its acceptance of the coalition position.

Senator **Harkin**. To introduce our third witness, I'd like to call on Senator Stafford.

Senator **Stafford**. Thank you very much, Mr. Chairman.

I would like to take this opportunity to introduce Ms. Dayna Caron of Johnson, Vermont, who is the next witness. Ms. Caron is the Secretary of the Board of Directors of the Vermont Advocacy Network, which is the organization that operates the P&A for mentally ill individuals in my home State.

This organization provides both lay and legal advocacy services to Vermonters who are currently receiving 24-hour psychiatric therapy.

Ms. Caron is also a member of various State and national organizations, including the National Alliance of Mental Patients.

Ms. Caron, we welcome you here today.

Ms. **Caron**. Thank you, Senator. It is really an honor, and it is a special honor for me to have my home Senator introduce and to be here on this Committee. It is a special treat. And thank you, Senator Simon and Senator Harkin and Senator Weicker, for coming to listen to us and inviting us to come and talk to you.

I myself am a former mental patient, and I guess one of the things I am here to tell you is that we can be involved in this system, and we do have an important contribution to make.

We have proven it in Vermont. As Senator Stafford said, I am on the Board of the Directors of the organization that is receiving the protection and advocacy funds.

What we have done is, using the current legislation, the legislation that you created, we have a comprehensive lay and legal advocacy system which involves both current consumer, ex-patients like myself, family members and attorney advocates.

Following the recommendation of our Advisory Committee, on which I served, our Protection and Advocacy Governing Board created an independent nonprofit corporation which is autonomous from the mental health system and from existing advocacy groups. The system is controlled by a Board of Directors, the majority of whom are people like myself—ex-patients and current consumers—and also, we have a mandated family membership, mandated on the Board.

Through the work of the Advisory Committee, we also were able to implement something which all of us are advocating for across the country. We added five advocates for the mentally ill to our Protection and Advocacy Governing Board which, of course I believe as you know, it is very important to have that representation in addition to the people who have been on there previously, representing the developmentally disabled. We added a family member, a mental health professional, and three current consumers to that board.

So our advocacy system, then, is one in which families, consumers and legal advocates are invested and involved.

We recommend that in considering the amendments to the current legislation, you encourage this cooperative and comprehensive lay and legal advocacy, having them work together under the same roof and work as a team, as opposed to perhaps contracting to separate consumer, family and legal groups individually, which could bring competition for scarce funding and could cause fragmentation of services.

Our system is now underway with advocates travelling throughout our rural State and making and receiving numerous toll calls in response to increasing reports of neglect, abuse and rights violation. An increase in our allotment—we are a floor State—would allow us to hire more advocates or to open satellite offices, which would increase our visibility and allow our advocates to spend more time with the clients and less time on the road.

Not all people eligible for Vermont Advocacy Network services yet know of its existence. Recently, the mother of a 13 year-old boy noticed that he was acting strangely. She thought that he might be delusional from some recreational drugs and took him to a clinic. From there, they sent her to a hospital emergency room, and he was then sent to the hospital psychiatric unit.

Some of the transferring of her son occurred without her permission. In fact, it appears that the hospital staff performed a spinal tap on her son without her permission. They had her sign a release after the fact.

The hospital does not have separate units for adults and adolescents, so that her son was housed with adults. There, the boy was originally treated with a drug to combat a possible street drug, then given antipsychotics, and later put on lithium. His treatment besides the drugs was six weeks in isolation, often in restraints. The boy was left alone for such long periods of time that he wet the bed. One morning, he was wheeled out of seclusion and apparently paralyzed. He was taken to another unit and, after tests, was suspected of having a neurological disorder. He was put on additional drugs and sent back to seclusion in the psychiatric unit.

The mother had not heard of our Vermont Advocacy Network. She did not know that there was anyone available to investigate the incident and advocate for her son. She was eager for help and is now relieved that the Vermont Advocacy Network is now actively investigating the case and advocating for the boy.

Currently, the State of Vermont, with only one State hospital, if you can imagine, is working toward regionalization—that is, serving all persons who are psychiatrically labelled in the community. There is widespread support for this concept of continuing deinstitutionalization, but of course we are all aware that there are pitfalls.

Our advocacy system must know where people are going once they leave the hospital so that it can ensure that eligible people have access to advocacy services. Therefore, Vermont Advocacy Network needs access to Vermont State hospital discharge planning records.

The protection and advocacy system also must be granted access to and copies of recently discharged clients' records that are being held by mental health centers. One community mental health center agreed to send a client's records for an outrageous fee. We cannot afford to pay for the records, nor can our advocacy system afford the expense of litigating the matter.

Therefore, it is imperative that the amendment to this legislation grant complete access to records held by community mental health centers.

In conclusion, I would like to on behalf of the National Alliance of Mental Patients urge you to increase funds for the protection and advocacy system and ensure greater access to records.

Thank you very much.

Senator HARKIN. Ms. Caron, thank you very much.

[The prepared statement of Ms. Caron follows:]

NAMP National Alliance of Mental Patient

% P.O. Box 618 • Sioux Falls, SD. 57101

TESTIMONY OF

DAYNA H. CARON
P. O. Box 512
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for the

NATIONAL ALLIANCE OF MENTAL PATIENTS

May 10, 1988

Hello, my name is Dayna Caron. I'm from Vermont. I am here today representing the National Alliance of Mental Patients. The National Alliance of Mental Patients is an organization that grew out of the Mental Patient Liberation Movement. We are all people who have experienced the abuses and deprivations of psychiatric institutions. Some of us have been involved with this movement for patients' rights for fifteen or twenty years. I became involved in 1985. I have been an in-patient in an institution in Kansas City and a community mental health client in Vermont.

The experience that we have had in Vermont addresses many of the issues raised in the reauthorization of PL 99-319. I will use our Vermont story to outline the concerns of the National Alliance of Mental Patients. In 1978, we first began organizing ourselves in Vermont for mutual support and to protect and defend our rights. As patients of psychiatric institutions we had our rights stripped from us on admission. We continue, after release, to live lives devoid of the usual rights, protection, and security that we all expect and trust is ours from birth.

In 1984, the people I work with in Vermont wrote a proposal to the Vermont Department of Mental Health and Vermont Board of Mental Health for an advocacy system in Vermont. The Board referred the proposal to the Commissioner of Mental Health who established an Advocacy Task Force composed of a diverse group of mental health advocates, professionals, attorneys, consumers, ex-patients and family members from around the state. Together they hammered out a report calling for establishment of an advocacy system that would be organized as an independent, non-profit corporation. It would be autonomous from the mental health system or existing advocacy groups; it would be controlled by a board of directors, the majority of whom would be consumers and ex-patients. They established that families would have strong input into the system through board membership and that the system would provide comprehensive lay and legal advocacy services. They also recommended that funding for the system come through the Protection and Advocacy Board which was then providing subcontracted services to the developmentally disabled through the Vermont Developmental Disabilities Law Project and the Vermont Citizen Advocacy Project.

At about the time that this Task Force was finishing its report in Vermont, your committee here was beginning hearings on abuses, neglect and rights violations in psychiatric institutions which led to the passage of PL99-319. It was exciting for the Task Force in Vermont to learn that there might be federal legislation to fund the very system that they were just now proposing. And let me remind you, this effort had come from the very people you had sought to serve with this legislation!

However, life was not to be quite that easy. Once the federal money became available, the struggle began for who and what would provide services. Initially the Protection and Advocacy Board which was controlled by Developmental Disability advocates and attorneys decided to ignore the Commissioner's Task Force Report and to head in the direction that they had taken with Developmental Disabilities. They decided to subcontract for services with the Developmental Disabilities Law Project and Citizen Advocacy. They went so far as to solicit proposals from interested parties and received proposals from our ex-patient organization, Vermont Liberation Organization, from the family group, Alliance for the Mentally Ill - Vermont, and from the Developmental Disabilities Law Project. All of this was done before the establishment of the Advisory Committee. It was at this point that I became involved. I was selected to be a member of the Advisory Committee. In deference to the Protection & Advocacy Board, it must be said that they did select a majority of consumers and ex-patients to be on the Advisory Committee. Family members were in addition to the majority we had.

The first action of the Advisory Committee was to recommend that none of the subcontractors' proposals be accepted. We felt that we had a blueprint for the kind of comprehensive advocacy system that we wanted in the Advocacy Task Force Report. We also had seen the problems of endless competition for scarce funding between competing advocacy interests; we were frustrated by the poor response of the professional advocates to our stated needs. We also were now becoming quite frustrated with their self-serving, high handed methods of supposedly serving us. We decided to work through the Advisory Committee to establish the kind of system we knew would work for us. It was a struggle. One of my compatriots on the Advisory Committee landed back in the hospital from the pressure. I was physically sick from the stress most of the time. After a few months, however, we were able to get five mental health advocates including three ex-patients and a family member appointed to the Protection and Advocacy Governing Board. With their presence and the help of a few sympathetic Developmental Disability advocates, we were able to get the Governing Board to accept the Task Force Report and to establish Vermont Advocacy Network. Vermont Advocacy Network is now fully underway, providing both lay and legal advocacy services to my brothers and sisters receiving twenty-four hour psychiatric supervision in Vermont. It should be noted that our original problem was the Protection & Advocacy Board's desire to subcontract to consumer, family, and legal groups individually. This only breeds competition among advocates for scarce funding and causes fragmentation of services. Our sister state, Maine, implemented such a system and it has broken down in disarray. Our system, however, has become a rallying point for families, consumers, and legal advocates. We recommend strongly that the amendment calling for consumer and family subcontracts recognizes this problem and encourages comprehensive lay and legal advocacy subcontractors rather than responding only to special interests groups.

I am secretary of our board of directors. Our president and vice-president are both ex-patients also. We have hired an excellent executive director, lawyer and lay advocates, some of whom are ex-patients themselves. We have established a budget of about $200,000 per year using carry over funds from the first years of funding. Vermont is a floor state with the minimum $125,000 allotment. Our ability to carry over and meet our budget will soon end unless you are able to authorize increased funding.

Vermont, as many floor states, is primarily rural. This means that advocates must travel throughout the entire state and make numerous toll calls. For Vermont Advocacy Network, these are considerable expenses. Further, the time that advocates spend on the road, decreases the time that advocates can spend with people eligible for our services. An increase in our allotment would allow us to hire more advocates or to open satellite offices in the state. This would increase our visibility throughout the state.

At this time, not all people eligible for Vermont Advocacy Network services know of its existence. Recently the mother of a 13 year old boy noticed that he was acting strangely. She thought that he might be delusional from some recreational drugs. Therefore, she took him to a clinic where they sent her to a hospital emergency room. At the hospital, her son was sent to the Psychiatric unit. Some of the transferring of her son occurred without her consent. In fact, it appears that the hospital staff performed a spinal tap on her son without her permission. They had her sign a release after the fact.

The hospital does not have separate units for adults and adolescents, so her son was committed with adults. There the boy was originally treated with a drug to combat a possible pleasure drug. Then he was given anti-psychotics. Later he was put on Lithium.

His treatment besides the drugs was six weeks in isolation, often in restraints. The boy was left alone for such long periods of time that he wet the bed. One morning he was wheeled out of seclusion and apparently paralyzed. The boy was taken to another unit. After tests, he was suspected of having a neurological disorder. he was put on additional drugs and sent back to seclusion in the Psychiatric unit.

The mother had not heard of us. She did not know that there was anyone available to investigate the incident and advocate for her son. Vermont Advocacy Network received an anonymous call from someone else. Finally, Vermont Advocacy Network was able to contact the mother. She was eager for help. At present Vermont Advocacy Network is actively investigating the case and advocating for the boy.

Vermont has one state hospital. Currently the Vermont Department of Mental Health is implementing its regionalization plan. As this plan is implemented, VAN must become a visible force throughout the state. Regionalization and its implementation present many concerns for Vermont Advocacy Network.

First, Vermont Advocacy Network needs to know where people are going once they leave the hospital so that it can ensure eligible people have access to advocacy services. Therefore, Vermont Advocacy Network needs access to Department of Mental

Health records.

Vermont Advocacy Network must also be granted access to and copies of the clients' records that are being held by mental health centers. One community mental health center agreed to send a client's records for an outrageous fee. VAN cannot afford to pay for the records nor can it afford the expense of litigating the matter. Therefore it is imperative that the Amendment to PL 99-319 grant complete access to records held by community mental health centers.

Access to records has also been an issue at the Vermont State Hospital. The hospital staff has set up barriers to reviewing records. Although Vermont Advocacy Network has been overcoming these barriers, it wastes time. Therefore, it is important that access to records language be strong and clear.

Another problem regarding regionalization is how the money is spent. It is important for VAN to monitor this process to make sure that the Department of Mental health is accountable for how it spends money. At present, much of the funding seems to be going to case management positions, even though there are serious deficiencies in crisis services. Further, the Department of Mental Health has made it difficult for Vermont Advocacy Network to review the proposals requesting regionalization money. These proposals are supposedly public, but after several requests they have not been provided. Again, trying to resolve this has taken up Vermont Advocacy Network staff time.

Another issue that presents itself as a current and potential problem is involuntary drugging in the community. At present, a person can only be involuntarily drugged at the Vermont State Hospital. When a person is at the Vermont State Hospital, he or she has the right to refuse drugging unless an independent hearing officer finds that the person is incompetent and under substituted judgment finds that medication is in the best interest of that person.

Recently a person released into the community under the regionalization- plan, refused to be drugged. Therefore, that person was taken back to Vermont State Hospital, where an involuntary drugging order existed. The person was readmitted, forcibly drugged, and released back into the community all in one day. The Department of Mental Health has proposed to involuntarily drug this person in the home.

Vermont Advocacy Network anticipates many problems should this be allowed. A person in the community needs to give informed consent to drugging and be told that he or she has the right to refuse drugs. If a person is not told of these rights, then that person must be able to follow some sort of established grievance procedure. If a person is to be involuntarily drugged, he or she must be granted the same due process considerations as one in the hospital.

Therefore, Vermont Advocacy Network needs to be able to monitor, review the procedures, and advocate for and with the individuals. This will take considerable time. At present there is a serious problem with Department of Mental Health's monitoring of the treatment in the community. No site plans exist for the community mental health centers, and the review procedure of the community mental health centers is cursory. Therefore, Vermont Advocacy Network sees itself as necessary to ensure that the people who are eligible for our services are treated with respect and that their federal and state constitutional rights are protected.

Vermont Advocacy Network never could have set in motion a full scale operation with $125,000. That amount could not allow us to fulfill the mandate of the law. Even with an increase to $150,000, Vermont Advocacy Network will have a $15,000 deficit in 1991 if it continues to provide quality services. Even at $150,000 our operation remains the same. Vermont Advocacy Network will have no money to hire additional advocates. At that point, Vermont Advocacy Network staff will have to spend considerable time to raise funds. We Board members hope we will not have to hold bake sales to raise funds.

NAMP **National Alliance of Mental Patients**
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Goals & Philosophy Statement for the National Alliance of Mental Patients

– To promote the human and civil rights of people in and out of psychiatric treatment situations, with special attention to their absolute right to freedom of choice. To work towards the end of involuntary psychiatric intervention, including civil commitment and forced procedures such as electroshock, psychosurgery, forced drugging, restraint and seclusion, holding that such intervention against one's will is not a form of treatment, but a violation of liberty and the right to control one's own body and mind. We emphasize freedom of choice for people wanting to receive psychiatric services through true informed consent to treatment which includes the right to refuse any unwanted treatments. We will also work to assure the rights of all people who have been psychiatrically labeled including but not limited to people in halfway houses, day treatment, residential facilities, vocational rehabilitation, nursing homes, psycho-social rehabilitation clubs as well as psychiatric institutions.

– To further the development of user-controlled alternatives to the "mental health" system and link these groups by having a national network. These alternatives can include, but are not limited to, self-help, peer support groups, drop-in centers, independent housing, cooperatively run businesses, advocacy and rights protection groups, and holistic healing centers. What they share is that they are structured and defined by the needs of the people creating and using the services, promoting empowerment, self-esteem, independence, and self-determination.

– To encourage the development of grassroots local, regional and statewide groups.

– To challenge the negative attitudes and lack of sensitivity of the public towards people who are psychiatrically labeled. These attitudes often lead to policies that stigmatize us and limit our exercise of basic legal, civil, and constitutional rights. We will work to educate and influence the public, especially the media, as to the importance of positive portrayals of people labeled "mentally ill," and work to promote public understanding and sensitivity.

– To improve the quality of life for psychiatrically labeled people by addressing housing, employment, legal and educational needs, and combatting discrimination in these areas. To address the needs of homeless and poor people, working to assure that all persons have a livable income. To advocate for fundamental changes in the public benefits system.

– To recognize that there is a diversity of viewpoints regarding the causes and the existence of "mental illness." We respect that all people are entitled to their own opinions on whether of not "mental illness" exists. No belief should be imposed on other people in defining themselves, their lifestyles, treatment or civil rights. None of these beliefs should be accorded the level and weight of established fact. The medical model is only one such viewpoint. Another viewpoint is that people who are experiencing distress are responding to real economic, social, familial, spiritual, and cultural pressures in their lives, and that labeling their real-life problems as "mental illness" does nothing but invalidate their feelings and experience. Therefore, when this organization uses terminology that reflects the medical model we will use quotation marks.

– To become recognized as a viable and representative national voice of, by, and for psychiatrically labeled people. To demand representation on any body which affects "mental health" and related issues including national commissions, committees, and mental health boards. We believe the mental health system must become more responsive to our needs and goals and be more accountable to the users of the system. Whereas we believe that all persons who identify themselves as users of the psychiatric system should be represented on forums that affect their lives, we will strongly advocate that those people who agree with our organization's goals and principles be adequately represented.

– To be an open and democratic organization representing the diversity of our constituency (race, class, gender, sexual orientation, physically disabled, and age). We recognize our obligation to reach out to groups that are underrepresented in our organization.

Senator Harkin. Before I open up for questions, I want to welcome Senator Simon and ask that if he has an opening statement or comments to please proceed.

Senator Simon. I have an opening statement, and I would just like to insert it in the record, Mr. Chairman. I just want to thank you for your leadership and Senator Weicker also for his consistent leadership.

Senator Harkin. Thank you very much, Senator Simon.

I would turn to the father of this whole thing for his questioning. Senator Weicker.

Senator Weicker. Thank you very much.

I have one question which I would like to have responded to briefly by each member of the panel. The enactment of this law, clothed you with the indicia of official status. As a practical matter, are persons getting into the institutions clothed with this official status to do the job envisaged by the legislation?

I mean, the whole purpose of this was, very simply, that one Congressional oversight hearing every ten years was not adequate protection for persons in mental institutions. So I have to ask, with this program, are the numbers of persons getting in there to do that oversight adequate?

Ms. Caron. We have had a continual struggle. It has been like one barrier, one hoop after another. We jump through one hoop, and then they put up another barrier. And it is really frustrating because it takes a lot of our staff time, and we have a small staff. So that is a problem. First, it was little I.D. cards, and then they thought of another reason, so it is a problem, and it is a continuing problem with us.

Mr. Rogers. The way we have done it—well, we have several problems—but two of the main ones that we are getting into the institutions, we established and funded a monitoring group, a monitoring committee project, that was working with the local mental health association, the State mental health association, and we have trained volunteers, and many of those volunteers and consumers/ex-patients of those institutions themselves. They go in in teams, as monitoring teams, and they do a very comprehensive job. They have a questionnaire that was developed by consumers—actually, consumers on the staff from my project, Project Share—which asked patients a whole list—it is a 20-minute questionnaire—about what are the conditions, are there abuse problems, has there been sexual abuse, have there been any other kinds of problems. So it is a pretty comprehensive sweep of the hospital. We also have a questionnaire of the staff. We go into the files, we look right in the files and the records and document whether or not there is discharge planning taking place, whether there is a diagnosis program for a treatment plan, et cetera.

The other project that we have developed is our lead project, which we call Leadership, Education and Development, which is training consumers. We go into a State hospital—it is a group of ex-patients themselves who are former patients of that hospital, who go in, and they have been trained in advocacy. They go into the State hospital, and they meet with sometimes as many as 100 or so patients, and basically given them training in advocacy services—what is available to them, how to get in touch with advocacy services, to recognize abusive situations and an appropriate kind of assertiveness training, because you don't want them to get into trouble; you want them to be able to deal with the situation and seek the help that is necessary.

As a result of this, we have actually instituted in one of our State hospitals where we are going to be closing the State hospital—the abusive situation was so bad in that State hospital, Philadelphia State Hospital, that Governor Casey agreed that we couldn't change the situation. We are now going to create a totally community-based alternative system to the State hospital, and we are in the process of a 2-year phase-down program. And I would say a good chunk of the reason for that is due to this legislation and the program that was established under this legislation.

Mr. SNAVELY. I might comment, we did a survey of our members, and we had responses from 30 States, and I think the overall statement that might be made is that it is very uneven in the different States. As far as access is concerned, I think there has been definite progress in achieving that. In terms of the quality of that access, what kind of information is obtained, how it is obtained and what kind of blocks are put in the way of people trying to obtain information and the extent of cooperation one gets, it varies substantially from State to State and locality to locality.

So I think as to the basic question, it certainly has made a contribution toward improving the opportunities for access and of raising the questions. In terms of achieving the objectives of the legislation, which was to really get at the question of abuse and neglect, I think we have a long way yet to go, with some exceptions. We have done very well in some areas, but we see evidences every day of a continuation of the kinds of conditions that this legislation was intended to preclude.

Mr. ROGERS. And of course, if we had more money, we could do more.

Senator HARKIN. Senator Stafford.

Senator STAFFORD. Thank you, Mr. Chairman.

I have just one question of Ms. Caron. What do you think should be the primary focus of the program in Vermont?

Ms. CARON. I think we have to ensure that—as you know, we have an adult abuse law, and so we are working with what we have in Vermont already established and utilizing those services and trying to coordinate the advocacy services. So we are working on rights violations, and then of course, neglect. As you know, we have many community care homes, and that is a really big problem; people are just abandoned in the countryside. And they do meet the eligibility requirements under this legislation.

So I think those are the two questions that we really have to focus on.

Senator STAFFORD. Thank you very much.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Stafford.

Senator Simon.

Senator SIMON. Yes. Mr. Rogers, you mentioned abuses taking place at 3 in the morning. What kind of abuses are we talking about that will take place at 3 in the morning?

Mr. ROGERS. Well, the gamut—sexual abuse, physical abuse. When I was in the hospital, during the daytime, in the day room, I smarted off to one of the staffpersons, and he said, "All right, that's fine. At 3 o'clock in the morning, I'll be back." And he was. And it was a slap on the side of the head and some punching kind of stuff. Luckily, I am relatively big, so it wasn't that bad.

Senator HARKIN. I was going to say, I hope he was pretty big.

Mr. ROGERS. He was—he also had other people behind him. But for a lot of folks, 3 o'clock in the morning is a really risky time, because there is no staff there. And you call the 800 number, and you don't get an advocate.

Senator SIMON. But at 3 in the morning, an 800 number might be available, say, in the State of Illinois or in a large State; but in Vermont, you are never going to be able to get an 800 number 24 hours—and I don't mean that disrespectfully of my good colleague from Vermont. But the reality is——

Senator STAFFORD. Well, there is usually somebody available by 4 o'clock, because that's when you have to get up and start milking cows.

Ms. CARON. Right. [Laughter.]

Mr. ROGERS. That's why we do the self-advocacy training. If you have in a situation people who know what their rights are and are aware of their rights and aren't as intimidated by staff, who are willing to report, to come together even sometimes in defense groups, then at 3 o'clock in the morning when there are no other advocates available, there may be the chance that the people could kind of bind together themselves and defend themselves.

Senator SIMON. OK. That leads to my next question. You talk about patients learning their rights. Do your three organizations also get involved in problems of the mentally retarded?

Ms. CARON. No, no.

Mr. SNAVELY. We at the National Alliance do quite a bit of work with the mentally retarded community in different States through coalitions, advocating for services in the community and advocating for different types of services that we have in common; we do that.

Ms. CARON. We do, in that many of our brothers and sisters are also labelled mentally retarded. Many people, as you know, are labelled mentally retarded and mentally ill, so many people who are also labelled mentally retarded are labelled mentally ill and are locked up in the institutions with us.

Mr. ROGERS. In our local organization, one of the things we are working with is a group called People First, which is a self-help organization of people with developmental disabilities. So there has been actually some cross-fertilization and training in our training programs.

Mr. SNAVELY. Senator Simon, could I just comment on your question on neglect and abuse. There is a particular type of neglect that is more subtle than the overt kinds of things that Mr. Rogers just explained, and I think that is the quality of the staff—the kind of training that is available, the kind of salary levels that are available, the actual ability to fill spots so that you are not substantially understaffed—in many of these facilities, you've got wages for technicians that are less than or equal to those that the people who are cleaning the hospitals are getting paid. These kinds of things create the conditions for a lot of the neglect and abuse that takes place. I think that this is a fundamental that affects many, many of the institutions across the country and would seem to me to be one of our primary targets. We need to deal with these structural problems if we are going to improve the protections and offer the kinds of services required by the people who are in these institutions.

Senator SIMON. I could not agree more.

I would just comment that if people who are articulate and can defend themselves a little bit are abused, I think the assumption has to be made that the abuse of those who cannot defend themselves has to be much greater. It is one of the areas we ought to be looking at.

Then, a final question, and Mr. Snavely, you refer to it in your testimony where you say,

> We are convinced that one of the negative consequences of deinstitutionalization without adequate community services is criminalization of persons with mental illness. Too many persons with mental illness are incarcerated in correctional facilities in lieu of treatment and other required community services.

Are your organizations also pushing on the community services side to help us move in that direction?

Mr. SNAVELY. That is a major thrust that we have, and I think all our organizations are working collectively as well as individually. In my particular State, we have had a major effort to get additional funding for housing and associated services and for improved quality of services and have been able to get substantialy increased funding—the word substantial is relative, to what has been previously available. But yes, that is a primary focus, but we have a long, long way to go because the amount of money that is required to do this is very substantial if we are going to make real headway in meeting these unmet needs.

Mr. ROGERS. If I may, in terms of what the Protection and Advocacy Program has been able to do, at least in Pennsylvania, towards that end is in our State, before there was Protection and Advocacy Program and our documentation—as Senator Weicker talked about how are we documenting and are we getting into these hospitals—before that, there was actually a consideration of shifting the locus of care back into institutions. Relatively quickly, we were able to document that these institutions for the most part are just not places to treat individuals, that even if you have a protection and advocacy system that it is not really the appropriate place for most people, and that what we needed to do was really create the community care.

So in our State, our Protection and Advocacy Program has been working in the systems advocacy change, which is another whole thing that we haven't really talked about, the whole systems advocacy area, to create legislation or work in educating and working in coalition with others groups to create legislation that would establish what we are calling single-stream funding or single responsibility programs in the community. So there is that kind of work going on as a result of this program.

Ms. CARON. Senator Stafford has helped us in this line. We have got a supported employment program, we received a large grant. We realize that that is one of the things that we need to keep us in the community. We need to have work, we need to be seen as viable human beings, and we need housing, and we need the support systems, too; we need clubhouses, and we need all those kinds of programs. So he has worked long and hard to get that program for us, for which we are beginning to see the results, and we are very, very grateful, because those are the kinds of supports we need. We need to maintain ourselves in the community.

I also wanted to mention in line with what you were saying that even though we can't have an 800 number that is available at 3 o'clock in the morning, I think that what Joe is saying about people knowing their rights and the fact that at 8 o'clock in the morning, there is a number that you can call and report it. That is why I would thank you all so much for creating this legislation, because the more incidents of abuse and neglect that are reported, a greater fear it will put into the people who are committing these incidents of abuse, and they will be less likely to continue because they know that they are going to be reported, once we start standing up to people and saying, "You can't do that anymore. We have a system in effect. We are going to protect these people." And if we begin to be seen as valuable human beings, then this cannot continue.

Senator SIMON. I thank all three of you.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Simon.

I want to focus on one thing that Mr. Rogers mentioned in his testimony and ask a general question about it. It would seem to me that active and meaningful consumer and family involvement would have a positive impact on the ability of the P&As to enhance the quality of life of mentally ill individuals.

Do you have a theory on why there is meaningful consumer and family involvement in some States, and in some other States, quoting from Mr. Rogers' testimony, "P&As are actively or passively resisting their legal obligations"?

Why is there meaningful consumer and family involvement in some States, and in other States, they are "actively or passively" resisting their legal obligations?

Ms. CARON. I think from our experience—and I guess a lot of times, Vermont is looked at as a model, because we really do have a really good system that is really an example of working together. And to be truthful about it, we really had to work very hard. We had a very well-organized ex-patient movement in the State. We had developed with the Department of Mental Health an Advocacy Task Force at the same time that you were holding hearings here, so that we knew we had a broad-based constituency of support for what kind of an advocacy system we wanted even before we knew there were going to be Federal funds to pay for it. And we were ready—when they told us they were going to appoint an advisory committee, that was the time that we started. We said, "These are the kind of people you should have." We nominated them. We worked very, very hard. And these are the kinds of professionals and parents we really encouraged who we thought would be good advocates for us on the advisory committee, and we had to stand up to the Protection and Advocacy Committee Board. I think that is something that has to happen in every State is they have to be fairly well-organized. Having well-organized ex-patient groups and well-trained advocates for themselves can make a big difference.

Mr. SNAVELY. I believe the problem is really in two parts. One is you can have families and/or consumer organizations that are not well-organized or not well-put-together and therefore do not have the kind of posture to engage the protection and advocacy organizations. You have another kind of problem where you may have good family and/or consumer organizations, but you simply are running into a lot of difficulty with the protection and advocacy organization itself because, one, they don't understand what mental illness is all about, and haven't made the distinction between that and the developmental disabilities, which is their historical involvement; and secondly, the question of how the P&A agencies are governed.

One of the points in the proposed amendments to this legislation is to strengthen the advisory councils so that with more involvement of consumers and families in the actual governing process the priorities and the policies recommended by them receive the consideration, we believe was envisioned in the original Act In many areas, we are closed out; we are simply closed out by the bureaucracy that is in place, which does act on the recommendation of consumers and families and we have to do something about that. I think the opportunity is there.

Part of the amendments that you are considering and for which we strongly advocate would strengthen the participation and role of these advisory councils. There was no point in setting them up unless you intended that families and consumers actually participate and have some influence over the priorities and the programs that are actually implemented by the P&A's.

Senator HARKIN. Very good.

Mr. Rogers.

Mr. ROGERS. Yes, that is a good question. I think, without psychoanalyzing each individual director—although it would be kind of interesting to figure that out—but overall, I think, on a systemwide basis, there was certain inertia. In other words, to get the program up and going fast, we put it into an existing program of the Developmental Disability Advocacy Network.

I think the sense I got from a lot of the folks, the directors of those programs, was that they were kind of used to dealing with a different kind of consumer. They were dealing with people with developmental disabilities. They had pretty good connections with the family organizations.

When we came along—and I think we are much more aggressive as a movement in terms of our rights protection and rights issues—quite frankly, I think they just didn't know how to deal with it.

So I think our hope is that with the amendment, that the advisory committee—which I think in the legislation, the original intent was very seriously put in there that there would be these advisory committees, that they weren't just tokens—that the amendment allows a very specific role for the advisory committee, which is setting the priorities jointly with the Governing Board. I think by giving a very specific kind of role, it will make it easier to fit into the system.

Senator HARKIN. Very good.

Thank you all very much for your participation and for coming great distances to be here today. We appreciate it very much.

Mr. Rogers. Thank you for having us.

Mr. Snavely. Thank you.

Ms. Caron. Thank you, Senator.

Senator Harkin. Our next panel consists of Eleanor S. Kohn, Vice President for Public Policy of the National Mental Health Association, Alexandria, Virginia; Steven Schwartz, Mental Health Protection and Advocacy Project of Northampton, Massachusetts; and Renee Bostick, President of the National Association for Rights Protection and Advocacy of Lansing, Michigan. I am told that Eleanor Kohn is really from Connecticut, although the Association is located in Alexandria, Virginia—but we'll welcome her wherever she is from.

Again, welcome. I'd like to officially welcome you all. And again, if I could call upon you in that order, and if you could summarize your testimony in five to seven minutes, I would be most appreciative.

Eleanor Kohn, from the National Mental Health Association, welcome, and please proceed.

STATEMENTS OF ELEANOR S. KOHN, VICE PRESIDENT FOR PUBLIC POLICY, NATIONAL MENTAL HEALTH ASSOCIATION, ALEXANDRIA, VA; STEVEN SCHWARTZ, MENTAL HEALTH PROTECTION AND ADVOCACY PROJECT, NORTHAMPTON, MA, ACCOMPANIED BY LORI INCROPERA, CHELMSFORD, MA; AND RENEE BOSTICK, PRESIDENT, NATIONAL ASSOCIATION FOR RIGHTS PROTECTION AND ADVOCACY, LANSING, MI

Ms. Kohn. I am also testifying on behalf of the Mental Health Law Project today, and I must comment, seeing that there are no lights, I have decided that one of life's greatest challenges is trying to finish your testimony before that red light goes on; I am glad we don't have it on today.

I am here today to talk about the role that the Protection and Advocacy Program has played in Connecticut as well as around the country and, of course, to urge the Subcommittee to reauthorize the Protection and Advocacy for Mentally Ill Individuals Act, with some minor amendments and of course some substantial increases in funding.

In Connecticut, this law has provided some funding for very important activities over the past couple of years. Unfortunately, because of the limited funding, the P&A agency decided early on that rather than attempting to spread itself around the State, they would limit their activities to just one region of the State, and it would cover just one State hospital.

The effort has been a worthwhile one. Of course, the gaps are tremendous. The agency has provided individual advocacy for 102 patients, most of whom have reported a variety of complaints, and when you start adding up those complaints, you come to some 1,100 contacts of various kinds. These abuse cases involve primarily exploitation, abuse, coercion, and inappropriate or excessive medical treatment. The neglect usually involved community services or a lack thereof, an inability to get people into appropriate services to help them to access the appropriate service which they needed at the time.

The P&A agency has also been very active in education and training programs, attempting to involve consumers, to empower them, to let them know what their rights are, to enable them to use the services that the P&A program is providing. They run some advocacy programs that have had to do with confidentiality; they have done some legislative work and have certainly aimed for bringing about system change in a variety of ways.

It is obvious that there aren't any simple answers to the problems we are trying to address. The difficulties that are encountered by people who have mental illnesses reflect very deeply-entrenched and very widely-pervasive attitudes about just who is valued in our society and who is not.

One trap that we can't fall into is to look for a quick fix. This is my 35th year as an advocate, as a volunteer with the Mental Health Association, and in all those years, I have lived through much of the quick fix mentality. We can't let that happen again. I believe that this program has the capability of providing a stability, of being a stable program of tested value, and I think that is one of the reasons that I agreed to come here and testify today. I think we need to maintain this program, but we need to beef it up to a level where it can provide services to the numbers of people who need them.

We still have a long way to go in Connecticut and in the Nation, but our experience in Connecticut has been that the advocacy organization has given us opportunities that we didn't have before.

Just let me give you an example, and I think Bill Snavely might reinforce this because he joined in this effort. In Connecticut, the Executive Branch announced a while back that they had the intention of utilizing State hospital grounds for the construction of a 400-bed jail. Political realities being what they are, the Department of Mental Health certainly was in no position to actively oppose the Administration's plans. Our P&A agency spearheaded an effort to strongly oppose what mental health advocates see as an additional stigmatizing and a potentially harmful effect on its hospitalized population. There were public education campaigns, there were media contacts, there was legislative advocacy. And frankly, the battle may not be won, but it would never have been mounted had there been no protection and advocacy agency in the State of Connecticut.

I believe I heard questions about how difficult it was to get access into State hospitals. There have been incidents of individual hospital staff offering what I would kindly refer to as token cooperation. But on the whole, the Department of Mental Health has not seen the Office of Protection and Advocacy as adversarial. They have been cooperative and are eager, I think, to see the agency exert whatever effect it can on the lives of the people that the Department is responsible for.

Like the NAMI Association, the Mental Health Association has also done a survey around the country which seems to indicate that for the most part, the protection and advocacy agencies, given the fact that they have only recently gotten off the ground, are operating effectively.

Some of our affiliates, however, did identify certain problems, which lead us to support some changes in the law. We are also part of a coalition which has developed recommendations for amendments to the law, and I am asking that that coalition proposal be entered into the record at this point. I believe you have it.

There are three issues around access. Amendments are needed to ensure that P&A agencies always have appropriate access to clients and to relevant client records. That is not always happening. Those agencies must know when a client has died. In Connecticut, they tell me there is one client who died under circumstances that are questionable, and so far they have not been able to get access to those records.

They must know about discharge planning sessions and be able to attend them. There is no prohibition against the P&A agency attending those discharge planning sessions at our State hospital, but nobody tells them when they take place.

And finally, they need to be able to have access to incident report meetings.

We are pleased to see that the draft bill that has been put together includes provisions that are going to accomplish this, with one exception. The bill does not give the P&A agency access to discharge planning sessions, but only to the papers that are prepared by the institution in connection with discharge. If any of you have had any experience with State hospital situations, you know that there is a lot of paper and not always a great deal of action. We are urging that that amendment be put in so that the P&A agency gets not just the papers that are involved with discharge, but also access to the meetings.

Eligibility. There has been dispute over whether the protection and advocacy system may use Federal funds to advocate on behalf of mentally ill people who are in Federal facilities.

Despite a 10-year history in the DD Protection and Advocacy Program, and despite the fact that there are no exclusions in the current law, the Administration has determined that P&As representing mentally ill clients may not represent those clients in Federal facilities. In some States, questions have even arisen as to whether the agency can represent mentally ill individuals when they are in prisons or in jails.

The intent of the P&A legislation was to focus on abuse and neglect of mentally ill individuals, and it doesn't make any difference where those people are—it shouldn't make any difference.

The Coalition recommends that the Committee clarify the fact that regardless of where the facility is, that those patients should be covered.

Finally, on to governing and advisory boards. Again, Connecticut's experience has been good in terms of representation. But there is serious question in Connecticut, and I suspect around the country, as to who those boards are advisory to. And I think that is an issue that needs clarification. Are they advisory to the governing board? Are they advisory to the P&A agency itself? Are they advisory to the directory? I think we need to have some clarification on that.

You have our figures, our recommendations for increases in funding. Just to substantiate those, the Coalition recommends $22 million in FY 89, $25 million in FY 90, and $30 million in FY 91. If Connecticut gets that kind of money, perhaps we will be able to expand these much-needed services into all five regions of the State rather than just having to limit it to one.

I thank you.

Senator HARKIN. Thank you very much, Eleanor Kohn, for that fine statement.

[The prepared statement of Ms. Kohn with an attachment follows:]

TESTIMONY SUBMITTED TO

SUBCOMMITTEE ON THE HANDICAPPED
COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

Regarding

REAUTHORIZATION OF THE FEDERAL PROTECTION AND ADVOCACY
FOR MENTALLY ILL INDIVIDUALS ACT, PL 99-319

Presented By

ELEANOR S. KOHN
VICE PRESIDENT FOR PUBLIC POLICY
NATIONAL MENTAL HEALTH ASSOCIATION
&
PRESIDENT OF THE BOARD OF DIRECTORS
MENTAL HEALTH ASSOCIATION OF CONNECTICUT

On Behalf Of

NATIONAL MENTAL HEALTH ASSOCIATION
MENTAL HEALTH LAW PROJECT

MAY 10, 1988

Mr. Chairman,

My name is Ellie Kohn. I am Vice President for Public Policy of the National Mental Health Association and a Member of the Board of Directors of the Mental Health Association of Connecticut. My testimony today is on behalf of the Mental Health Association and the Mental Health Law Project.

The NMHA is a voluntary, citizens advocacy association, organized in forty states through 650 local affiliates. MHAs work for improved services and treatment for people with mental illnesses, advocate for increased research into the causes and prevention of mental illness and work to promote mental health.

The Mental Health Law Project is a Washington-based public interest organization advocating for the rights of mentally disabled children and adults in the United States.

I am here today to talk about the very important role the Protection and Advocacy program has played in Connecticut, and to urge the Subcommittee to reauthorize the federal Protection and Advocacy for Mentally Ill Individuals Act, with minor amendments and substantial increases in funding.

In 1986, a new law, PL 99-319, authorized federal funds for mental health advocacy services to protect the rights of mentally ill people in residential facilities (hospitals, nursing homes, group homes, board and care homes, half-way houses and similar facilities). These funds were to be distributed through the already established Protection and Advocacy Systems set up under the Developmental Disabilities Act, most of which also act as the Client Assistance Program under the Vocational Rehabilitation Act as well. Under PL 99-319, these agencies were given the authority to investigate individual incidents of abuse and neglect of mentally ill persons and to pursue administrative, legal and other appropriate remedies. The P&As are also authorized to effectuate "system change" in the way services are provided to mentally ill people generally.

This new law has provided funds for some very important activities in my state of Connecticut over the last two years.

Due to the limited funds available under this Act, Connecticut's P&A agency decided to focus on one area of the state, so as to be able to provide effective advocacy to a specified target area. The agency has provided individual advocacy for 102 individuals with 1,138 case problems. Abuse cases primarily involve exploitation, abuse, coercion and inappropriate or excessive medical treatment. Neglect usually involves community service, medical and mental health treatment or personal care needs of clients. In cases involving protection of rights, the major issues we dealt with were privacy, financing and reimbursement issues and guardianship or conservatorship problems.

If we have learned one thing in Connecticut, it is that there are no simple solutions to the problems we are trying to address. The difficulties encountered by people with mental illnesses in Connecticut reflect deeply entrenched, widely pervasive attitudes about who is valued and who is not valued in our society. One trap we must not fall into, is to look for a quick fix.

The Connecticut P&A sees its job as more than lobbying for a fresh coat of paint on the walls of an institution, and more than advocating for individuals to be released from institutions. According to our P&A office: "Many of the people whom we serve have been deeply wounded throughout their lives. They have been wounded by various human service providers, ranging from schools to hospitals. Some have been physicially and emotionally abused by family members. Just as it has taken time to amass these societal wounds, it will take time to heal them."

As a long-time advocate for people with mental illnesses, this rings true to me and reflects the sentiments of the Mental Health Association nationwide and the Mental Health Law Project.

We still have a long way to go, in Connecticut and in the nation, but our experience indicates that advocacy organizations can use the opportunity afforded by the P&A legislation to work together for significant changes. I emphasize my support of the involvement of consumers in such activities and my belief that state mental health authorities will respond in a constructive, rather than defensive, manner.

The rest of my testimony discusses the federal law, amendments proposed to that Act by a coalition of six mental health organizations and the National Association of Protection and Advocacy Systems and the proposed draft bill shared with us by the Committee staff.

You will find attached to my statement a detailed set of recommendations from the Coalition. I would like to highlight some of the more important proposals in that document, particularly in relation to the draft bill.

A recent survey of Mental Health Associations around the country indicates that P&A agencies are generally operating effectively. Most have few problems in investigating grievances, pursuing remedies, or accessing records. However, our affiliates did identify certain problems, which lead us to support the following changes to the law.

Access Issues

Amendments are needed to ensure that P&A agencies always have appropriate access to clients and relevant client records. Access to facilities, residents and their records is essential if the P&As are to fully serve the needs of their clients. Yet experience with the program shows that the law is not sufficiently clear with respect to certain situations: when a client has died, discharge planning sessions, and incident report meetings. The P&A should have authority to investigate a case of death in an institution, and the technicality that the individual no longer resides in the institution should not prevent such investigations.

Since eligibility for advocacy services continues 90 days following discharge from the facility, P&As need to be able to assist a resident with this transition from institution to community, by participating in the discharge planning process. It is important for the P&A to be aware of post-discharge arrangements, including application for various federal and state benefits, coordination with community mental health providers and appropriate housing, and the law should be amended to give the P&A agency access to discharge planning sessions.

The P&A should also have information on incidents which occur in the facility involving clients of the P&A and should have access to reports of incidents of abuse and neglect prepared by the facility staff and have the right to attend meetings which review such reports.

We are pleased to see that the draft bill includes provisions that will accomplish this, with one exception. The bill does not give the P&A agency access to discharge planning sessions, only to the papers prepared by the institution in connection with discharge. Since the major problem with discharge planning in many facilities is that it is a paper exercise, without appropriate follow-up to ensure that the community agency to which the patient is to be referred knows when the patient is being discharged, where the patient can be reached and exactly what the treatment regimen has been in the institution, this amendment will not adequately address the problem.

We urge that in addition to having access to discharge papers, the P&A also have access to discharge planning sessions in the institution.

Eligibility issues

Dispute has arisen as to whether P&A systems ay use their Federal funds to advocate on behalf of mentally ill individuals residing in Federal facilities. Despite a ten-year history in the DD P&A and despite the fact that there are no exclusions in the current law, the Administration has determined that P&As representing mentally ill clients may not represent clients in federal facilities. In some states, questions have also arisen as to whether the P&A agency can represent individuals when they are in prisons or local jails.

The intent of the P&A legislation was to focus on abuse and neglect of mentally ill individuals, and not on the particular residential facility in which they reside. Accordingly, the coalition recommends that the Committee clarify that facilities owned and/or operated by the Federal government are covered under this Act and further that P&As have the authority to investigate, upon request, charges of abuse or neglect of mentally ill individuals residing in prison and jails.

The draft bill does not adequately deal with either of these issues. There is no mention in this bill of coverage of Federal facilities, and instead of clarifying that P&As should have access to mentally ill people in the custody of the corrections systems, the bill calls only for a further General Accounting Office study. The coalition believes that there is sufficient information already available as to the extent to which local jails have become an alternative institution for many mentally ill people who should instead be in a treatment facility. We urge the committee most strongly to protect the rights of these individuals. P&As should have the authority to respond to requests for assistance by family members or by clients themselves when seriously mentally ill people are placed in jails or prisons and their mental health needs are ignored or they are subject to abuse, as defined in this law.

I cannot urge you too strongly not to postpone action on this problem by authorizing one more study which is unlikely to be acted upon for another three-years (when the P&A law is up for renewal again).

The terms "inpatient or resident" used in the Act also seem to exclude assistance to individuals who are in the process of being admitted to a facility. Frequently people who are voluntarily entering a residential setting need assistance with matters such as continuation of their federal or state benefits, maintenance of the family home or child care. Further, individuals who have been picked up by the police and brought to a hospital may have need for legal assistance. Again, we are pleased to see that the draft bill addresses this problem so as to cover individuals who are in the process of being admitted to a facility, or being transported to a facility.

Governing and Advisory Boards

Some problems have arisen in some states, although not in Connecticut, in ensuring that the mental health expertise on the advisory board is fully available to the governing board of the P&A. In some states, advisory boards are not playing the role envisioned when the legislation was enacted, and are not fully participating in the decisions around priorities of the

P&A with respect to advocacy services for people with mental illness.

To better integrate the advisory board into the P&A system, the draft bill jointly charges the advisory board and the governing board with the responsibility for deciding upon the priorities of the agency. while the governing board, continues to have the final authority, since it carries the legal responsibility for the agency.

The governing board of private non-profit agencies should also include representation by individuals who are knowledgeable about mental illness, including families of mentally ill individuals, consumers of mental health services and lay advocates for mentally ill people. The draft bill would accomplish this by requiring the governing boards of the P&A to be broadly representative of all the clients served by the system. In addition, the chair of the mental health advisory board should be given a seat on the P&A governing board.

Funding

It is apparent that even with no changes in the law, the funding levels currently authorized are inadequate to enable the P&As to fully protect mentally ill people against abuse and neglect in residential settings and to advocate on their behalf. In Connecticut, for example, we are anxious to see the P&A's activities extended throughout the state. The additional responsibilities recommended above, many of which are included in the draft bill, make the need for expanded funding even more compelling. Another difficulty is the discrepancy between the funding for the DD P&A activities and the funding for activities to assist individuals with mental illnesses. At the state level, advocates for mentally ill persons compare the needs of the dd population and mentally ill population and the sizes of those populations, and expect the activities of their P&A to reflect these factors. In actuality, all P&As must give greater attention to persons covered under the DD program, simply because of federal appropriations. This is not a rational way to run the system.

To adequately provide protection and advocacy services for mentally ill people, substantial increases in the authorizations are necessary. The coalition recommends $22.0 million in FY 1989, $25.0 million in FY 1990 and $30.0 million in FY 1991. The draft bill authorizes only $14.3 million in FY 1989, $18.5 million in FY 1990 and $23.5 million in FY 1991.

The Coalition clearly believes the higher recommendations made by our organizations more accurately reflects the need for substantial increases in P&A funding. The increase we recommend would bring the appropriation for the P&A for mentally ill people more in line with the appropriation for P&A services for persons with developmental disabilities, ($19.1 million was appropriated in FY 1988 for the DD P&A and the FY 1989 authorization is $22 million). Our recommendations would also provide more meaningful amounts to the many states which receive only a minimum allotment.

With the inclusion of the amendments specified above, we urge expeditious reauthorization of the P&A law for an additional three years, through FY 1992.

March 28, 1988

COALITION RECOMMENDATIONS FOR REAUTHORIZATION OF PL 99-319

(PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS)

This document, endorsed by a coalition of mental health organizations active in advocacy on behalf of people labeled mentally ill, recommends that Congress reauthorize the Protection and Advocacy for Mentally Ill Individuals Act for three additional years with few major changes in structure, authority or operation. The program's continuation as currently constituted, but with substantially increased funding, is necessary for the orderly development of assistance to mentally ill people in residential settings.

Although PL 99-319 was authorized for three fiscal years, 1986 through 1988, the first fiscal year saw no activity. The Act was passed in May and grant awards were issued in September. As of March 1, 1988, therefore, the program has been operational for seventeen months. A full assessment of the program must await more operational experience.

However, based on information received from Protection and Advocacy Systems as well as other advocacy groups, we recommend modifications in several areas where specific issues have been identified in a sufficient number of states to warrant legislative attention. These include:

- composition of the governing authority of the PAMIs;
- role of advisory boards in developing policies and priorities;
- PAMI access to facilities and records;
- expanded eligibility for PAMI services;
- client grievance procedure and public comment on system's annual policies and activities;
- minor changes in administrative procedures;
- authorization levels.

1. Composition of the governing authority

Although a significant number of P&As have added representatives of the mental health community to their governing boards, many states still have agencies whose boards lack members knowledgeable about the special advocacy needs of people with mental illness. Since board members are often appointed for multi-year terms, an immediate change in composition is not practical.

The coalition recommends the follow addition to Section 105, System Requirements:

"( ) establish a governing authority which

(a) by October 1, 1990, for systems organized as private non-profit entities or public systems with multiple-member governing authorities, is broadly representative of the clients served by the system;

(b) approves the annual statement of priorities developed jointly with the advisory board; and (*)

(c) selects its members according to its own policies and procedures, except that, for private non-profit organizations, the chair of the advisory board shall be a member of the governing authority."

The coalition understands and intends the word "approves" in ( ) (b) above to mean that the governing authority may accept or reject priorities jointly planned with the advisory board, but may not modify them or substitute policies and priorities at variance with those presented for its approval. It further understands and intends that the "approval" authority granted under this subsection would permit a governing body to reject a portion of the jointly planned priorities and implement the balance. In the event jointly planned priorities are rejected in full or in part, those rejected elements could be reviewed and revised through the joint planning process and resubmitted for approval. The joint planning process, as envisioned under this subsection, is flexible to the extent the planning activity could be done through a joint sub-committee or by delegation to the advisory board alone, or through other mutually agreeable arrangements which retain the essential features of involvement of the advisory board in the process and a requirement for advisory board consent to the priorities advanced to the governing authority for approval.

2. Role of the Advisory Board to a PAMI

Under current law, each PAMI must have an advisory board to "advise the system on policies and priorities...." Member groups of the coalition have received reports that in some states the recommendations of advisory boards have been ignored because the boards had no real connection with the actual decision making-process in the agency, i.e. the governing authority. (NAMI will supply examples.)

The coalition recommends the following change in the current advisory board language designed to promote greater advisory board involvement in the priority setting process. (additional wording underlined; deleted words in parentheses):

"(6) establish an advisory board

(a) which will develop, jointly with the governing authority, an annual statement of (policies and) priorities to be carried out in protecting and advocating the rights of mentally ill individuals; and...." (*)

The change will require the governing authority to fully engage the advisory board in developing the agencies policies and priorities. The final approval of the policies and priorities, however, would remain with the governing authority.

3. Access to Facilities and Records

Access to facilities, residents and their records is essential to PAMIs fully serving the needs of their clients. Many PAMIs have been able to obtain state legislation authorizing needed access or negotiated agreements with state officials. PAMIs in several states, however, are reporting resistance to full access to facilities and barriers to needed client information. A few PAMIs have reported that prior appropriate access disintegrates when the PAMI files litigation or engages in other aggressive advocacy activity. Other complaints include refusal to allow access to records of a deceased resident or one whose whereabouts is unknown. (See endnote 1 on p. 7, infra).

The coalition recommends the following changes to strengthen the access provisions in the statute: (new language underlined)

"Section 105 (a)(4)(B)...

(i) who by reason of the mental or physical condition of such individual (including individuals who have died or whose whereabouts are unknown) is unable to authorize the system to have such access."

Two other concerns raised by PAMIs involve the need to assist a resident with the transition from institution to community and information on incidents involving residents which occur in the facility. Since eligibility for advocacy services continues 90 days following discharge from the facility, it is important for the PAMI to be aware of post-discharge arrangements, including application for various Federal and state benefits, coordination with community mental health providers and appropriate housing.

The coalition recommends amending Section 105(a) to add a new number (5) and renumber existing paragraph 5 through 7 accordingly:

"(5) have access to discharge planning sessions conducted in the facility and access to reports of incidents of abuse and neglect prepared by the facility staff to attend meetings which review such reports."

4. Expanded Eligibility for PAMI Services

a. Coverage of Federal facilities

PAMIs have received requests for services from Veterans Administration hospitals, Department of Justice prisons, Immigration and Naturalization Service facilities. The NIMH Office of General Counsel contends that Federal facilities are not within the scope of the PAMIs' authority. (copy of opinion attached). Congressman Henry Waxman has formally advised NIMH of Congress' intent to cover Federal facilities. (letter attached). Finally, P&As have a ten year history under the DD Act of representing persons with developmental disabilities in Department of Defense schools.

The coalition recommends adding language clarifying that "facility rendering care or treatment" (Sec 102) includes all such facilities owned and/or operated by the federal government. The statement of managers in the conference agremeent on 99-319 said (p.15) "The intent of the legislation is to focus on abuse and neglect of mentally ill individuals and not on the particular residential facility in which they reside. Accordingly, residential facilities could include, but need not be limited to, hospitals, nursing homes, community facilities for mentally ill individuals, and board and care homes." (The statement is repeated almost verbatim on p.16) Congress, through statutory or report language, should expand on this statement emphasizing that the nature of the ownership of the facility is similarly not a factor in determining eligibility for PAMI services. Allotments to PAMIs are available to pay for services to mentlly ill individuals who are residents of private facilities and all levels of publicly owned facilities (federal, state and local).

b. Coverage of state or local jails and prisons

State prisons and particularly local jails have become the dumping ground for mentally ill people who break the law or are accused of law violations (sometimes involving minor infractions which may grow out of their illnesses) and receive little or no care or treatment while jailed. The abuse and neglect of people in these settings, while not comprehensively documented, is well known through wide-spread anecdotal reports.

The legislation does not clearly authorize PAMIs to investigate incidents of abuse and neglect in state and local prisons and jails, particularly the non-forensic units. The coalition recommends the addition of statutory language authorizing PAMI involvement on behalf of individuals diagnosed as mentally ill who are involuntarily in residential settings where care or treatment may not be provided.

c. Coverage of individuals in admissions process

The terms "inpatient or resident" seem to exclude assistance to individuals who are in the process of being admitted to a facility. Frequently, people who are voluntarily entering a residential setting need assistance with matters such as continuation of Federal benefits, maintenance of the family home or child care. Further, individuals who have been picked up by the police and brought to a hospital may have need for legal assistance. The coalition recommends expanding the terms "patient or resident" to include individuals who are in the admissions process, but not to include assistance at commitment hearings.

5. The coalition finds the changes made in the P&A title of the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (PL 100-146) wholly salutary and recommends their inclusion in the reauthorization of P.L. 99-319 in Section 105(a):

"( ) on an annual basis, provide the public with an opportunity to comment on priorities established by, and activities of, the system."

"( ) establish a grievance procedure for clients or prospective clients of the system to assure that mentally ill individuals have full access to services of the system."

As part of the public comment process, the Committee report should state that the PAMI is to make available its annual budget for public examination.

6. Minor changes in administrative procedures

a. Use of volunteers - The coalition believes that PAMIs should be encouraged to increase their use of volunteers, including consumer volunteers, by requiring them to report on the extent to which volunteers provide services (new language underlined).

"105(a)(7)...a report describing the activities, accomplishments and expenditures of the system (including the extent to which the system is utilizing volunteers in the delivery of advocacy services) during the most recently completed fiscal year."

b. 5 percent limit on training - The coalition believes that the limitation of 5 percent on PAMI spending for technical assistance and training (section 104(b)(2)) is counter productive and should be deleted.

c. increase in minimum allotments - The coalition recommends including in the reauthorization the text of Section 301(b)(7) of the DD Assistance Act (PL 100-146). The section provides for increases in minimum allotments when the appropriations increase in any year is greater than the growth in the CPI.

d. annual application and assurances - Unlike the Developmental Disabilities Act and the Rehabilitation Act, P.L. 99-319 requires each PAMI to apply annually for its allotment and for the Governor to provide "assurances" that certain conditions are met. The coalition feels that the requirement is an unnecessary administrative burden and, more importantly, delays grant processing. The application process is redundant since only the P&As can apply. Once the governor has given his assurances, they remain in effect until the governor indicates otherwise. The coalition recommends that the application and assurance process apply only when statutory changes require new or additional assurance or when the governor is planning a redesignation of the agency.

e. sub-contracting - The coalition recommends modifying the language on sub-contracting to provide that the PAMI should consider entering into contracts with self-help groups made up individuals or families of individuals covered under the act. Self help groups have been highly effective in rights education and self-advocacy skills training. While the language would not mandate a contract with such groups, it would enable self-help groups to participate more equally with others in a contracting process.

f. technical assistance - NIMH, the agency responsible for providing technical assistance to the PAMIs, indicates that it has discretion to determine the proportion of total appropriated funds it may use for the purpose. The coalition recommends modifying section 115 to read as follows: (new language underlined)

"Sec.115 The Secretary shall provide technical assistance to eligible systems with respect to activities carried out under this title in accordance with the expressed needs of the eligible systems. No more than two percent of appropriated funds may be used for technical assistance."

7. Authorization levels

It is apparent that even with no changes in the law, the funding levels currently authorized are inadequate to enable PAMIs to fully protect mentally ill people against abuse and neglect in residential settings and advocate on their behalf. The additional responsibilities recommended above make the need for expanded funded even more compelling. The coalition recommends authorization level identical to those authorized for DD P&As in PL 100-146, as follows:

FY 1989	$22,000,000
FY 1990	$24,200,000
FY 1991	$26,620,000

Endnote 1: To supplement Issue 3 on p. 3: The National Association of State Mental Health Program Directors (NASMHPD) has advised NAPAS that we will use our best efforts to informally overcome access problems if we are given a lists of the states where obstacles exist and the nature of the obstacles. So far, we have not received the list. It is NASMHPD's intent that all PAMIs have suitable and appropriate access to state facilities and client records.

Dissents to coalition positions.

* The National Association of Protection and Advocacy Systems (NAPAS) dissents from the coalition position on joint development of policies and priorities between the governing authority and the advisory board. PAMIs have been diligent in establishing and using advisory boards in a manner consistent with both the letter and intent of PL 99-319. Inevitably, some PAMIs will develop smooth working relationships easily and quickly; others will require more than 17 months. However, no foundation has been established for the need to create a complicated and awkward new process for developing policies and priorities. In the absence of information on wide-spread breakdowns in working relationships, Congress should not legislate change, particularly one that mandates an elaborate and untested nation-wide procedure. Further, NAPAS questions the wisdom of Congress legislating a process which may interefere with the legal responsiblities of a PAMI's governing authority. Finally, the process, NAPAS contends, would be completely unacceptable and unworkable in PAMIs which operate under a board of commissioners or other multi-member authority established by state statute.

The National Alliance for the Mentally Ill (NAMI) considers this provision to be essential to the integrity of the consensus recommendations and its acceptance of the coalition position.

Senator **Harkin**. Next we will turn to Steven Schwartz, Mental Health Protection and Advocacy Project, Northampton, Massachusetts. He is accompanied by Lori Incropera.

Ms. **Incropera**. Yes. My name is Lori Incropera, and I live in Chelmsford, Massachusetts.

My father was a patient at Worcester State Hospital from February through December of 1987. My father was a healthy 77-year-old man, living independently at the elderly housing project in Holliston until January of 1987. He was admitted to Harrington Hospital in January with a notation in his record stating, "The patient is a well-developed, well-nourished, alert individual who does not appear to be in acute distress."

He was only there for two weeks before he was transferred to Worcester State Hospital in four-point restraints and a body net, without prior notification to any family members. The family was distraught at the prospects of my father's confinement at a hospital due to its reputation and its history of being a callous, heinous and grossly mismanaged institution.

Once we were notified of the situation, my family made several attempts to transfer my father to a suitable nursing home. We could not locate even one nursing home which would accept him because he was living in a State hospital.

We were never informed of his medical diagnosis, despite our repeated attempts to staff personnel. The family continued to monitor his condition. We would visit him at the hospital as well as take him to our home. The social worker worked with us for 1 month and then lost interest in my father's case. She maintained that no nursing home would take him and that the institution's environment was suitable for his needs.

He was visited by my sister on December 15th, at which point we were alerted by the nurses that he appeared to be very rundown. We maintained daily contact, and all feedback was that he was fine. But when my sister went to pick him up on Christmas Day, she found him slumped over a chair, foaming at the mouth, with an elevated temperature. She requested to see a doctor and was told no.

On December 26th and 27th, the same scenario occurred. He was still slumped over the chair, foaming at the mouth, losing weight, and now showing signs of dehydration. The on-duty staff still insisted he was fine and denied any requests we made to see a doctor.

On December 28th, I went to see him, and he was still in the same chair, passed out, now totally incoherent and gaunt. He exhibited ulcer sores on his lips, dehydration, an encrusted mouth, and he was aspirating. I perceived him to have pneumonia, due to his medical history and the symptoms that he was exhibiting.

The nurse indicated that an x-ray had been taken, and the x-ray was negative. We were outraged at the lack of concern or response from the institution. We demanded that he be sent to U Mass Medical Center, due to its proximity and its reputation.

While we were waiting, I finally managed to get some petroleum jelly from the L.P.N., who was the only nurse on staff at that time. I lubricated his lips enough to get some liquids into his system. Only then did I realize that he was too incapacitated to drink.

The emergency room physician examined the x-ray, and to his disbelief, proclaimed that it was in fact someone else's x-ray. He proceeded to take a stat x-ray, which revealed pneumonia. He completed a thorough examination, with the following diagnosis: pneumonia of the lungs; fungus of the toenails from the filth in the institution; total dehydration; inflammation of the feet and ankles; possible spinal meningitis due to the severe inflexibility of his skeletal frame, which was later attributed to his sitting in the chair for such a long period of time.

A nurse from U Mass said, and I quote, "This is the worst case of neglect" she had ever seen from Worcester State. She was totally disgusted at his care at the State hospital. The doctor said, and I quote, "When a patient arrives in this condition, we cannot expect him to live through the night." He died on January 14th, 1988.

My family felt a terrible injustice had been done, and for no reason. We continue to believe that his death could have been avoided. We received no assistance or guidance from the Department of Mental Health, the State hospital, or from any of the health facilities that he had been with. However, I did receive media requests from people associated with the Department of Mental Health, Internal Affairs Division, which is appointed to investigate itself. They came across to me as self-serving and trying to scramble and cover up the situation.

It was at this time that I came upon a newspaper article concerning the Center for Public Representation and its probe into several unexplained deaths at Worcester State. I called the Center and spoke with attorney Steven Schwartz, who has since guided me through all of the interrogations and legal bureaucracy and has been the only light of consistency for me and my family during this time of need. Without him and the Center he represents, we wouldn't have a clue as to where to turn or who to believe.

This has become one massive cover-up operation under the guise of an elderly person who died a normal death. The bottom line is that people in responsible positions ignored their responsibilities to care for him and to protect his Constitutional rights.

Nothing will bring my father back. However, I feel that his death has and will serve a purpose. When the incidences surrounding his death became public, several people in similar situations called me to share their experiences of mistreatment of their loved ones in State hospitals. I have been able to offer these people some direction and reassurance by referring them to the Center for Public Representation, which has set up a project to help other people in life-threatening situations.

One person in particular has sought the Center's help, whose sister was in a similar situation as that of my father. The Center was able to help her by locating a suitable nursing home for her sister and thereby avoid another sad situation. She called to say, "thank you and God bless you."

Funding for these efforts to protect the mentally handicapped is essential. Otherwise, people such as these and myself will be abandoned.

Thank you.

Senator HARKIN. Lori, thank you very much for a very poignant and very powerful statement, really showing what this is all about.

We appreciate your coming here and doing it; I know it is tough for you do it, but I appreciate it very much.

Ms. Incropera. Thank you for having me.

[The prepared statement of Ms. Incropera follows:]

TESTIMONY OF

LORI INCROPERA

Senate Subcommittee
on the Handicapped

Reauthorization of the Protection & Advocacy
For Mentally Ill Individuals Act

May 10, 1988

Senate Subcommittee on the Handicapped
Washington, D.C.
May 10, 1988

I. INTRODUCTION

My name is Lori Ann Incropera and I reside in Chelmsford, Massachusetts. My father was a patient at Worcester State Hospital, Worcester, Massachusetts, from February through December, 1987.

II. DAD'S HISTORY

My father, Hokan Enquist, was a healthy, self-supporting 77 year old man who was living independently at the elderly housing project in Holliston, Massachusetts until January, 1987. When he became noticeably more forgetful, the family decided to place him in the Masonic nursing home in Charlton, Massachusetts. My father had devoted most of his livelihood to the Masonic cause during his life, and we felt they would show their appreciation by caring for him in one of their homes.

Upon admission, he had a complete physical examination at the request of the nursing home. This examination revealed a strong, healthy man. He was at the nursing home for approximately nine days when his personality problems became aggravated. Without notice to anyone, or even a good reason, he was transferred to the Harrington Hospital in Southbridge, Massachusetts, solely upon the written request of the medical physician on duty at the Masonic Home.

He was admitted to Harrington Hospital on January 30, 1987 with a notation in his record stating: "the patient is a well-developed and well-nourished, alert and oriented individual who does not appear to be in acute distress." He was only there for two weeks before he was transferred on February 13, 1987 to Worcester State Hospital in four-point restraints and a body net, again without prior notification to any family members. My oldest sister, Shirley Tutuny, was called late that night, after he had already been admitted. The family was distraught at the prospect of my father's confinement at this hospital due to its reputation and its history of being a callous, heinous and grossly mismanaged institution. In fact, the Hospital had been sued in 1985 by the Justice Department for violating the constitutional rights of its residents.

III. THE YEAR AT WORCESTER STATE HOSPITAL

Once we were notified of the situation, the family made several attempts to transfer my father to a suitable nursing home. We could not locate even one nursing home which would accept him because he was living in a state hospital. We were never informed of his medical diagnosis at the time of admission to Worcester State, despite our repeated questions to staff persons. We tried hard to work with the social worker at Worcester State Hospital in an attempt to ascertain what the plans were for my father's treatment and discharge.

The family divided the responsibility to monitor his condition amongst the several children. We would visit him at the hospital as well as take him to our homes. The social worker worked with us cooperatively for a month, but then lost interest in my father's case and became increasingly evasive. When we were able to talk with her, she maintained that no nursing home would take him and that the institution's environment was suitable for his needs. This situation continued for several months.

Dad came home for a visit on Thanksgiving. Everything seemed normal, so we made plans for Christmas. He was visited by my sister on December 15, at which point we were alerted by the nurses that he appeared to be very run down. We maintained daily contact with them through December 24 by telephone; all feedback was that he was "fine." But when my sister picked him up on Christmas Day, she found him slumped over a chair, foaming at the mouth, with an elevated temperature. She had called earlier and was told at that time that he was "fine and ready to go". She noticed that his regular food tray was untouched. She requested to see a doctor and was told "no." On December 26 and 27, he was again visited by family members and the same scenario occurred. He was still slumped over the chair, foaming at the mouth, losing weight, with signs of dehydration. The on-duty staff still insisted he was fine and denied any request we made to have my father seen by a doctor. We knew that since it was the weekend, no one would listen or respond to our requests for help.

On December 28th, Monday morning, my sister and I went to see him. He was still in the same chair, passed out and slumped over as before. He was now totally incoherent and gaunt. He exhibited ulcer sores on his lips, dehydration (as witnessed by inflammation of the feet and ankles), and an encrusted mouth. He was aspirating. I also perceived him to have pneumonia, due to his medical history and the symptoms he was exhibiting.

The nurse indicted an x-ray had been taken which was negative. We were very anxious about his condition and outraged at the lack of concern or even minimal response from the institution. We demanded, since no help was obviously available at this institution, that he be sent to UMass Medical Center in Worcester. This hospital is nearby and has a good reputation. We stated that we would not leave until he was transferred to another facility.

While we were waiting for an ambulance, his regular tray of food arrived with no liquids whatsoever. His breakfast tray was still in front of him, untouched. I finally managed to get some petroleum jelly from the LPN. I lubricated his lips enough to attempt to get some liquids into his system, which an aide took from someone else's tray. At this time, I realized he was too incapacitated to drink because of the aspiration and the large amounts of flem he was excreting.

Dad finally arrived at UMass via the ambulance at 1:10 p.m. The Emergency Room physician examined the x-ray that was sent along with my father and, to his disbelief, proclaimed that it was, in fact, someone else's x-ray! He proceeded to take a Stat x-ray which, not surprisingly, revealed pneumonia. He completed a thorough examination with the following prognosis:

- pneumonia of the lungs
- fungus of the toenails
- total dehydration
- inflammation of the feet and ankles
- possible spinal meningitis due to the severe inflexibility of his skeletal frame which was later attributed to his being in a stationary position (i.e. chair) for an extended period of time.

Dad was immediately placed on an IV of D5W and IV antibiotics, along with a Foley Catheter. A nurse from UMass said this was the "worst case of neglect she had ever seen come from Worcester State". She was totally disgusted at his care at the state hospital. The doctor said that, "When a patient arrives in this condition, we cannot expect him to live through the night." Dad died on January 14, 1988.

Ironically, after my father had been hospitalized for seven months, the Justice Department and the Commonwealth of Massachusetts signed an agreement in August 1987 settling the federal lawsuit. The state insisted that the conditions at Worcester met constitutional standards, but agreed to take additional steps immediately to improve the psychiatric and medical care for the residents. The Justice Department disagreed with the state's plan, but took no action. Unfortunately, this agreement has made no difference for at least six residents, all of whom died in the five months following the settling of the case. It seems to me that this case did not change anything at the state hospital.

IV. NEED FOR LEGAL ASSISTANCE

My family felt a terrible injustice had been done and that a vital part of our family had been taken from us, prematurely and for no reason. We continue to believe that his death could have been avoided. We received no assistance or guidance from the Department of Mental Health, the state hospital, or from any of the health facilities with which my father had been associated. However, I did receive media requests for interviews and for information requests from people associated with the Department of Mental Health's Internal Affairs Division which was appointed to investigate itself. They came across to me as self-serving, and trying to scramble and cover up the situation. Ironically, I had been trying to contact these same agencies and key hospital administrators while I witnessed my father's condition deteriorate, but I never even received a return call. The doctor from the UMass Medical Center was the only person who offered any form of compassion or assistance.

It was at this time that I came upon a newspaper article concerning the Center for Public Representation and its probe into several unexplained deaths at Worcester State Hospital. I called the Center and spoke with Attorney Steven Schwartz, who has since guided me through all of the interrogations and legal bureaucracies and has been the only light of consistency for me and my family during this time of extreme trauma. Without him, and the Center he represents, we wouldn't have a clue as to where to turn or who to believe. This has become one massive cover-up operation under the guise of an elderly person who died a normal death. The bottom line is that my father was healthy one week and dead the next, and people in responsible positions ignored their responsibilities to care for him and to protect his constitutional rights.

V. CONCLUSION

Nothing will bring my father back to us. However, I feel that his death has and will serve a purpose. When the incidences surrounding his death became public, several people in similar situations called me to share their experiences of similar mistreatment of their loved ones in state hospitals and the frustration of dealing with the DMH. I have been able to offer these people some direction and reassurance by referring them to the Center for Public Representation, which has set up a Project to help other people in life-threatening situations. One person in particular has sought the Center's help, whose sister was in a similar situation as that of my father. The Center was able to help her by locating a suitable nursing home for her sister and, thereby, avoided another sad situation. She called to say "thank you and God bless you."

Funding for these efforts to protect the mentally handicapped is essential. Otherwise, people such as these and myself will be abandoned.

Senator **Harkin**. Steven Schwartz, welcome to the Subcommittee.

Mr. **Schwartz**. Let me say, Senator, at the outset, that it is serving people like Lori, her family, and the six other people who have died at Worcester in the last 5 months that makes this program worthwhile in Massachusetts. It is what makes my work over the last 15 years so rewarding. I know it makes your contribution to this program so vital. And I hope it makes people across the country in institutions like that aware of how grateful we are.

Let me also remind you that this hospital where Ms. Incropera's father was, Worcester State Hospital, is a hospital in which the United States Justice Department chose to sue Massachusetts, because they felt the conditions were unconstitutional. This is the Justice Department that was questioned by Senator Weicker in the first round of hearings for this particulate statute. The Justice Department settled that case. They entered a consent decree in August of 1987. They said that they were satisfied that the hospital was now a decent place to live. Five months later, six people had died. Four of the six were under 35 years old. They all died under conditions that were not just suspicious, but were outrageous.

I am the Director of the Center for Public Representation, which is a public interest law firm in Northampton, Massachusetts. We are the protection and advocacy agency in our State. We have offices at most of the State hospitals in Massachusetts. We receive $177,000 in Federal funds. We work with five other legal organizations in Massachusetts. And by combining State and Federal money and then by asking for in-kind contributions from every participating organization, we have managed to have a full-time person at seven of our eight State hospitals.

We don't cover the Bridgewater State Hospital, which is a hospital where forensic clients go in our State. It is the hospital where another six people died in the last nine and a half months, despite a federal court order that was overseeing that case.

One of my clients who died there, who I am representing with the help of the protection and advocacy system, is a man who was sent to Northampton, another one of our hospitals, for 42 years because he fell off a tractor and had a brain injury. He spent 42 years at that hospital, and then he was transferred to Bridgewater. Of the 4½ months he spent at Bridgewater, every single minute of every single day, waking or sleeping, he was restrained. When he was sent to Bridgewater, he went with a medical record on his chest that said, "Only pureed food. Soft diet only." He died because the Bridgewater State Hospital staff gave him a hotdog, and he choked to death.

At each of our State hospitals in Massachusetts where the P&A Program is, we do have unimpeded access to our clients, to their clinical records, and to the wards on which the people live. The access is not limited to clients who formally request the program's assistance. On the contrary, each of our offices have initiated an aggressive outreach program to contact individuals not capable of seeking help. These vulnerable clients are our highest priorities.

I want to suggest that with respect to access, I think it is these clients that the Committee needs to consider more than anybody else. And there is no provision right now that makes clear that individuals who are not capable of calling an 800 number, individuals who are not capable of reaching out and touching people because they have been institutionalized for a long time, or individuals who suffer from severe disabilities, deserve the Protection and Advocacy Program's assistance. And in State after State where I have been, access has been denied uniformly where clients are not capable of calling the P&A. And if that is the type of access that is permitted, I would suggest that the best intentions of the legislation will not be served.

We do have a priority process in Massachusetts. As a result, our local offices focus on abuse and neglect; individuals who are appropriate for release but are still confined; those who are involuntarily being medicated, and those whose civil rights are being violated.

In 1987, we were able to serve 700 people. This year, we expect to be able to serve 1,200, not including an additional 500 people who are part of two Federal lawsuits which we have brought.

As I mentioned, several of our clients are people who have died, like Ms. Incropera's father and my other client at Bridgewater.

As a result of these deaths and the serious abuse at these hospitals, we have initiated several systemic reform projects which try to address the underlying conditions at the hospital. One is our Lifeline/Death Alert Project, which is an attempt to provide 24-hour telephone assistance and onsite advocacy to families like Lori's, who will call us, we hope, and for whom we can get to the hospital within a few hours and begin to advocate for their loved ones.

We were originally intending to focus the project on those people who had died. Then we realized that that was not really the right place where we ought to start; it is preventing people from dying that we need to be attentive to. And in doing that, I think all of the P&As can pay attention to what it is possible for them to do.

I was here last week, and I had the good fortune of spending a few hours at the Vietnam War Memorial. I wondered whether it might not be appropriate for the P&As to produce a list like that, because I think it would shock this Committee and shock the American people if they see there is a black wall actually out there with names of people, hundreds and thousands of people, who have over the last century given their lives in State hospitals the way Ms. Incropera's father did.

I have also had the good fortune of being able to consult and visit P&As around the country. I have seen 15 programs, and I can report to you a few generalized comments about those visits.

The first is that the P&As have made remarkable progress in developing a national network of advocacy programs dedicated to protecting the rights and enhancing the dignity of people who are labelled mentally ill. I think that is undisputed by everyone--participants, observers, and even critics of the system.

I think it is also clear that the clients of these programs have obtained demonstrable and measurable benefits, whether that be described in terms of less hours of physical restraint or more responsive services.

And I also think it is clear that Congress' original interest in creating these P&A programs can best be served and furthered by reauthorizing them.

Let me just finish by making a few general observations about these P&As around the country.

First, there is a remarkable degree of consistency about whom they are serving. Almost all the P&As have chosen to focus on residents of public mental health hospitals. This emphasis is consistent with the findings of the Subcommittee several years ago concerning the most serious incidences of abuse and neglect. It reflects the reality that our public mental hospitals in this country are dangerous places where vulnerable handicapped persons are at exceedingly high risk of being harmed, overmedicated, or even dying.

In effect, I think this Committee should know that the P&As are now serving the most needy clients.

There is also a remarkable consistency in who they are not serving. Solely, I think, as a result of lack of resources, the mandate in the bill has not produced consistent advocacy services at private psychiatric hospitals, at nursing homes, at juvenile facilities, in jails, in community residences, in board and care homes, or in other 24-hour settings. It is simply not possible with the resources that they have been given to cover even the State mental hospitals.

In Georgia, where I spent a week, there is one hospital that prides itself on being the largest State hospital in the United States. It speaks glowingly of the fact that at one time not more than 20 years ago, there were 17,000 people locked up in that one hospital. Now it says they have come a long way because there are only 3,000 people confined there. And I suppose in a statistical measure, that's a lot of progress. If you are one of the 3,000, though, it is not really a very new generation that they see.

For that 3,000-bed hospital, there is one half-time paralegal assigned in Georgia. They still do not cover all of their hospitals with that allocation of resources.

So I think it would be unrealistic for the American people or the Congress to believe that with what is now available, we are going to cover nursing homes, jails, community residences, private psychiatric hospitals, and the host of other places.

There are access problems, in response to questions from the Subcommittee before, but I think those problems are not so much can we get into facilities, because I think for the most part, P&As are getting into facilities; it is can we reach the people who can't call us.

In almost every State that I have been—not every State, but most States—there are rules that say the P&A staff can only go see the people who have called for their help. That essentially writes off the most vulnerable and most needy clients.

There aren't many standards that guide our activities. There aren't criteria to tell us when we are doing well. There are some clients who care and who can give us feedback, as Lori has to me. But for most of us, what we really need to know and what we take our solace from, I think, is knowing that our work is about advocating for the clients themselves and taking directions from them.

When I look across the country, what I have seen is that P&As speak for or in behalf of individuals who are handicapped. Almost all of the programs are not telling the clients what to do or what is in their best interest. Instead, they are the sole voice of the clients who can't speak for themselves.

In those places where priorities have been set—and there are many, although there are some that have not—the focused programs usually target their resources on the most compelling violations, like death, physical abuse, sexual abuse, and excessive restraint and overmedication. And those are, sad to say, the bread and butter of what happens in most of our State facilities.

In my view, the governing board issue that has been presented to the Committee is not one that I see as a significant problem in most of the 15 or 20 States that I have had contact with. In those States, the governing boards and particularly the advisory boards are working together reasonably well. The governing boards are paying attention to the advisory boards; the advisory boards, in many ways because of this Subcommittee's initiative, are comprised of consumers and family members.

You have taken a great step, I think, in the original Act in mandating 50 percent representation. You have done what has not happened in any other mental health or disability program across this country by giving consumers and family members a voice, and a mandated voice at that.

I think the governing boards and the various organizations have paid heed to that; they have respected Congress' intention, but much more importantly, they have respected the consumers themselves.

And so my suggestions are fairly simple—that the P&A bill ought to be reauthorized as is; there should be very few, if any, changes; there should be, of course, additional resources; and I would probably not tamper with any of the governing board/advisory board relationships.

Thank you very much.

Senator HARKIN. Thank you very much, Mr. Schwartz.

[The prepared statement of Mr. Schwartz with an attachment follow:]

TESTIMONY OF STEVEN J. SCHWARTZ
TO THE SENATE SUBCOMMITTEE ON THE HANDICAPPED
OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES

HEARINGS ON THE REAUTHORIZATION OF THE PROTECTION AND ADVOCACY FOR MENTALLY ILL INDIVIDUALS ACT OF 1986

May 10, 1988

I. Introduction

My name is Steven J. Schwartz. I am the director of the Center for Public Representation, a public interest law firm in Northampton, Massachusetts. The Center is the protection and advocacy agency for Massachusetts and has offices at most of the public mental hospitals in the Commonwealth.

I testified before this Subcommittee in April 1985 and worked together with your staff in drafting the P&A legislation. Since then I have served as a consultant to more than fifteen states in designing and implementing their federal programs. I have also served on the board of directors of the National Association for Rights Protection and Advocacy for the past five years. I would like to share with you my observations of many of those P&As, as well as to describe the structure, accomplishments, and challenges of the Massachusetts program.

II. An Overview of the P&A Programs

During the last year I have visited P&A agencies in Washington, New Mexico, Louisiana, Georgia, Rhode Island, Maryland, and the District of Columbia. I have consulted by telephone with programs in Vermont, Connecticut, Delaware, Wyoming, Arizona, Wisconsin, and Texas. I am also reasonably familiar with, and have previously visited, P&A agencies in five or ten more states. Based upon this experience, I have learned a great deal about the various strategies, approaches, and systems chosen to implement the federal mandate.

That the P&As have made remarkable progress in developing a national network of advocacy programs dedicated to protecting the rights and enhancing the dignity of people labeled as mentally ill is undisputed by all participants, observers, and even critics of these systems. That the clients of these programs have obtained demonstrable and measurable benefits, whether described in terms such as less hours of restraint or more responsive services, is also beyond cavil. And that Congress' interest in creating these systems can be best furthered by reauthorizing them, in their same form, is an assumption I hope is shared by everyone, including the Subcommittee.

In light of my familiarity with advocacy systems in more than half of the states, I feel comfortable beginning with the premise that the P&As are currently fulfilling their legislative mandates. I would like to take this opportunity to move beyond this premise and honestly and openly share my views of the strengths and needs of these systems.

A. The Clients of the System

In general, there is a remarkable degree of consistency in the design and activities of the various state programs. Most P&A systems have chosen to focus on residents of public mental health facilities. This emphasis is consistent with the findings of this Subcommittee several years ago concerning the most serious incidents of abuse and neglect. It reflects the reality that public mental institutions are dangerous places where vulnerable handicapped persons are at exceedingly high risk of being physically harmed, dangerously medicated, and even dying. Statistical data, media investigations, legislative hearings, and most importantly, consumer experiences uniformly confirm that limited resources should be directed to assisting residents of state hospitals. In effect, the P&As are now serving the most needy clients.

There is also a remarkable degree of uniformity amongst states with respect to the clients who are not currently being served by the P&As. Almost entirely as a result of the lack of resources, there is little consistent advocacy for persons labeled as mentally ill in private psychiatric hospitals, nursing homes, juvenile facilities, jails, community residences, board and care homes, or other twenty-four settings in the community. Agencies attempt to be responsive to all requests for assistance from whatever location, but the harsh reality is that services to nonhospitalized persons are sporadic at best. While the legislative mandate of the protection and advocacy system is extensive, the resources appropriated are clearly inadequate to permit it to fulfill these expectations. Absent a substantial increase in funding, it is unlikely that most programs will move beyond public mental health facilities for the next several years.

B. Barriers to Full Implementation

1. Access

The programs still confront serious obstacles to accomplishing their mandate. In several states such as Georgia and New Mexico, public administrators have erected a myriad of barriers between P&A staff and their clients. Access to hospital wards and residents is frequently limited, allegedly to "protect" the clients welfare or privacy. Despite huge facilities that consume hundreds of acres and countless buildings, with multi-million dollar budgets, state hospitals often claim there is insufficient space to provide the P&A program with even a small office and telephone in an area adjacent to their clients.

2. Eligible Clients

I believe many P&As have misread the intent of the Act. By focusing on the language requiring investigation of complaints, some programs have hesitated to serve persons who have not affirmatively requested assistance or for whom a complaint has not been initiated by a concerned party. This unduly passive approach in effect excludes institutionalized persons who are incapable of seeking help or who are uninformed that their rights are being violated. It conveniently obfuscates the reality of large, segregated facilities whose residents are often intimidated by staff and who have become accustomed to being ignored when they speak out. It also incorrectly assumes that all hospital residents are sufficiently competent to request advocacy services despite years of hospitalization and/or the presence of severe handicaps. Thus, while virtually all programs are serving institutionalized persons, many of them are attempting to do so from offices which are hours away from the hospital, pursuant to access restrictions imposed by the facility which are intolerable, and with intake procedures which may penalize the most vulnerable and least capable clients.

3. Standards

The systems created to deliver protection and advocacy services within institutions need further refinement. There simply is not much information or experience, particularly in certain states, about appropriate service delivery structures for state hospital residents. With one or two exceptions, there has been little evaluation of mental health advocacy services. There are only a few articles describing standards for effective institutional advocacy programs. More needs to be done to establish guidelines for quality services and to transfer existing knowledge amongst the states, so that the urgent need of protecting mentally ill individuals in state facilities is undertaken in a skillful and effective manner.

Despite this lack of guidance, the P&As have generally adopted a client-centered perspective on advocacy. They recognize that consumers' views have traditionally been disregarded and that their preferences are commonly ignored. In determining who to advocate for, the P&As are unique in their commitment to respecting the directions and choices of people with disabilities. They have eschewed the tendency to substitute the advocate's view of what is best for their clients and instead have opted to respect the preferences of those for whom they advocate. In so doing they honor traditional ethical precepts which govern legal relationships, while simultaneously empowering the very people who for so long have been neglected. In almost all states with which I have consulted, the programs consider themselves as the voice of people with disabilities who need assistance in expressing and achieving their goals, and not as the directors or determinants of their clients' fate.

4. Priorities

Given the huge numbers of persons labeled as mentally ill in public facilities and the pervasive infringement of their rights, it is obviously impossible for the P&As to assist all residents who need their help. Clear priorities must be established through a credible process which includes consumers, family members, and other advocacy organizations. Unfortunately, some programs have not engaged in such a process, leaving advocates struggling with overwhelming demand and consumers disenfranchised from the decisionmaking process. In those states which have formulated system priorities, the clarity of the program's focus and the legitimacy of its efforts have significantly improved. But even without the benefit of priorities, most P&As have identified similar issues which require their persistent advocacy. Virtually all programs with which I am familiar regularly address problems of abuse and neglect, excessive restraint, and release from institutional confinement to more appropriate and less restrictive settings. They have usually targeted their resources to the most compelling violations of residents' civil rights. Their efforts have made a marked difference for those without the ability to protect their own interests, safety, and dignity.

C. Structure and Staffing

There are also variations amongst the P&As. Some have elected to employ only attorneys and paralegals, focusing primarily on legal rights protection. Others have extensively recruited consumers and developed peer advocacy components. Still others have combined these approaches or adopted permutations on this theme through the use of family volunteers, community educators, and public policy analysts. Staffing patterns, system design, and program integration with other advocacy organizations varies considerably, depending in great part on the advocacy model employed. These differences have generally been healthy, reflecting both local needs and the merits of experimentation. But some greater uniformity may be desirable in the future. With increased evaluation and the advent of standards, the P&A programs should move towards a consensus on the most effective models, methods, and strategies for implementing the Congressional mandate under the Act.

Finally, there has been much ado concerning the formal structure of the P&As, as reflected in the relationship between the agency's governing board and the program's advisory board. Frankly, the clamor seems far out of proportion to the reality. In all the states with which I am familiar, there is not only a genuine respect for the views of the advisory board but a definite deference to their directions. In Georgia, for instance, the advisory board is responsible for all critical aspects of the program. While there are certainly some exceptions to this pattern, particularly in those states where the designated organization is a public agency as opposed to an nonprofit corporation with its own board of directors, the reality appears to be that the P&A advisory boards have a substantial role in the implementation of the program. In fact, the legislative mandate concerning the percentage of consumers and family members on these boards has enshrined them with a special legitimacy and authority. In my experience, this is hardly an issue which merits further Congressional attention.

III. The Massachusetts P&A System

A. Structure and Services

The protection and advocacy system in Massachusetts is managed and directed by the Center for Public Representation. It received approximately $177,000 in federal funds during FY'87. Services are provided by the Center and five other legal advocacy organizations that already had experience in representing institutionalized persons and previously maintained a limited presence at a state hospital. By combining state and federal resources and securing significant in-kind contributions from each participating organization, the P&A has established an office on the grounds of seven of the eight state hospitals in Massachusetts. Each office is comprised of a full-time paralegal and a part-time attorney. A senior attorney and experienced paralegal with the Center oversee and coordinate the network, provide technical assistance and training to local staff, and direct all systemic reform activity.

Each hospital office serves institutionalized residents at that facility and, to the extent possible, responds to requests from other eligible clients. In practice, however, the P&A offers very limited, if any, services to individuals in other settings. In fact, solely as a result of the lack of resources, it does not maintain an office or offer meaningful assistance to residents of the state's forensic, adolescent, public health, or correctional institutions.

At each state hospital the P&A has unimpeded access to its clients, their clinical records, the wards on which they live, and the staff responsible for their care. This access is not limited to clients who formally request the program's assistance; on the contrary, each office has initiated an aggressive outreach effort to contact individuals not capable or free to seek help. These vulnerable and often silent clients are the program's highest priority.

Through a lengthy process, the P&A has established individual and systemic priorities. Local offices focus on serving clients who are allegedly subject to abuse or serious physical neglect; who are appropriate for release but will otherwise remain confined; who are threatened with the involuntary administration of psychotropic medication;

or whose civil rights are being violated. In addition, each office is responsible for designing and implementing a project which is consistent with the P&A priorities and which addresses a particular aspect of the facility or mental health delivery system.

B. Individual Cases

With its $177,000 in federal funds, the P&A represented more than seven hundred clients in FY'87. This number should rise beyond twelve hundred in FY'88, not including several hundred classmembers in two federal lawsuits. Several of its clients are persons who have died as a result of seriously inadequate medical care, excessive restraint, inappropriate hospitalization, and intentional abuse. One died at the Bridgewater State Hospital after being restrained every minute of every hour of his more than four month confinement. Despite a warning in his medical record that he should only be fed pureed food, he was given a pork hot dog and choked to death.

One local office intervened to help a homeless man who was threatened with involuntary hospitalization solely because he had no other place to live. The advocate assisted in locating an alternative residential setting in the community, thereby avoiding a potentially lengthy and expensive hospitalization. Another office represented a client whose guardian withheld her Social Security checks and refused to spend these resources to assist the individual in transferring to a noninstitutional alternative. The advocate assisted in having the guardian removed and another person substituted in his stead. The new guardian is now managing the client's funds so that she can live in an appropriate community setting.

C. System Change Initiatives

The P&A has created three major system reform projects designed to address some of the underlying conditions which contribute to the ongoing and persistent violations of institutionalized persons' rights. The Lifeline-Death Alert project will provide a twenty-four capacity to respond to life-threatening situations and facilitate timely advocacy interventions directed at preventing unnecessary deaths in state hospitals. It will also monitor the investigation of these incidents by the Department of Mental Health. If appropriate, it will support legal and other strategies to remedy perceived rights violations. A copy of a description of this project is attached as Appendix A.

The P&A will also undertake to analyze data and evaluate the practical effectiveness of the Department's client grievance and investigation system. Finally, the P&A will lead a community education and advocacy effort to ensure that newly-funded community residential programs are not built on the grounds of state hospitals, as proposed by the Governor. The project will also seek to ensure that persons who are unnecessarily and inappropriately institutionalized are placed in these less restrictive alternatives.

IV. Recommendations

Based upon my experience in Massachusetts and other states, I would offer the following recommendations to the Subcommittee for consideration in reauthorizing the Protection and Advocacy Act:

1. The language and substantive provisions should remain essentially unchanged. There is no compelling reason for modifying the mission, mandate, or requirements of the P&A systems. Absent a dramatic expansion of resources, the number of eligible clients should not be increased, by removing the ninety day limitation or otherwise.

2. Legislative authorization for unimpeded access to clients, their residences and their records, regardless of the severity of their disability or their capacity to request help, is essential to assist institutionalized persons. A requirement that state facilities which confine large numbers of eligible clients provide P&A programs with reasonable office space at these institutions should also be included in the Act.

3. Funding levels should be significantly raised just to enable the programs to serve eligible clients as presently defined under the Act.

4. The application process for federal funds should be streamlined. Assurances should be accepted for the term of authorization of the Act, in order to simplify the receipt of the funds allotted for each state.

5. The limitation on training expenses is unnecessary and should be removed. The role and amount of technical assistance provided by NIMH should be clarified.

V. Conclusion

Thank you for the opportunity to speak with you today. As a result of Congress' initiaative and leadership during the past several years, there is now a dedicated and skilled complement of advocates who will continue their efforts to protect people who are labeled as mentally ill. With your continued support, and hopefully with an increase in funding, the P&A programs are a strong foundation upon which a system to prevent abuse and safeguard the rights of institutionalized persons can be built.

CENTER FOR PUBLIC REPRESENTATION

22 Green Street, Northampton, MA 01060

MENTAL HEALTH PROTECTION & ADVOCACY PROJECT
DISABILITY LAW CLINIC

413/584-1644 x 265
586-6024 (TTY)

Memorandum

To: P&A Attorneys & Advocates

From: Cathy Costanzo

Re: Project to Monitor Client Deaths at DMH Facilities

Date: February 9, 1988

After much discussion we have elected to name the initiative to monitor client deaths at DMH facilities the "Life Line-Death Alert Project." The project as presently envisioned has four components relating to information flow, investigations, remedial actions, and affirmative or preventative interventions. A discussion of each follows.

I. INFORMATION

This category involves not only the flow of information from sources external to the P&A, but also within the project itself. It includes the following:

(1) Department notification to the Center for Public Representation each time a death occurs. There has been one recent communication with the Commissioner in which he indicated a willingness to share information with the P&A. We have arranged a meeting with Dick Ames to negotiate an agreement about timely notification of any DMH client deaths at the Department's inpatient facilities or in general hospitals after an individual has been transferred from a DMH inpatient facility. We will also attempt to be informed of the individual's name, although we feel confident about your ability to learn this information informally, should the Department not be cooperative.

Although we have discussed also monitoring the deaths of DMH clients in community programs, we have elected to view this as a second phase of this project for several reasons. We are concerned about the scope of such an initiative and our mutual capacity to implement it successfully. In addition, it will be a more controversial negotiation with the Department, given the magnitude of such an undertaking. Lastly, it constitutes a departure from the Project's priorities to represent institutionalized persons and should be considered in the context of priority setting.

(2) The Center for Public Representation will notify the appropriate local office immediately upon learning of a death. The information accompanying this notification should include: the hospital; ward; date of death; the client's name; and any known circumstances surrounding the death.

(3) Within forty-eight hours after notification, the advocate will seek to determine any other useful information concerning the death, including family name and address, and other facts.

(4) CPR will be responsible for contacting family members and for securing a release of information.

(5) The local office, in conjunction with CPR, will be responsible for evaluating the initial facts regarding deaths of individuals at DMH inpatient facilities. The nature of this evaluation will be to make a determination about whether an investigation is indicated.

(6) The Center for Public Representation will be responsible for contacting the Central Office of the Department to recommend an investigation in all instances where it appears to be warranted and where the hospital chief executive officer determines not to conduct a full investigation.

(7) In extraordinary cases, CPR will contact the media to inform them of a death at an inpatient facility. This will be evaluated on a case by case basis.

(8) The P&A project via CPR will analyze and periodically publish information pertaining to the deaths of individuals at DMH inpatient facilities.

II. INVESTIGATIONS

1. The Mental Health Protection and Advocacy Project will, as a matter of policy, encourage and advocate for the participation of the family of the deceased resident in all investigations.

2. Where the P & A is retained to represent the family, has represented the client, or in other unusual cases, the Center for Public Representation or local attorney will attend all interviews or meetings between the family and the assigned investigators.

3. CPR will contact DMH to ensure the safety of other at-risk residents whenever there is strong evidence that the conditions which causes a death imperil the safety of other residents. This will be done by phone and in writing.

4. The Center for Public Representation will monitor the timeliness and comprehensiveness of the investigation. When an investigation is deficient with respect to either of the above referenced qualities, CPR will be responsible for notifying the Department.

5. The Department will share the investigation report with CPR, even when the Center is not representing the deceased resident's family or the P&A had not previously represented the individual. CPR will be responsible for negotiating this access with the Department.

6. The Center for Public Representation will share the investigation report with the local office and MHLAC.

7. The local office, in conjunction with CPR and MHLAC, will be responsible for evaluating the adequacy and the responsiveness of the report.

8. CPR will contact the Department to request the correction of any inadequacies in the report.

9. In exceptional circumstances, CPR will contact the media when necessary.

III. REMEDIAL ACTIONS

A decision about the most appropriate remedy will be determined in large part by the facts unique to each individual case. The following represent some of the options identified as worthy of consideration:

(1) Each case which is fully investigated should be reviewed for a potential civil rights action. This screening will be done by CPR, but MHLAC and local offices are encouraged to make recommendations.

(2) CPR, in the context of its P&A activities, will accept a limited number of civil rights cases. All others will be referred by the Center.

(3) A statewide referral panel will be developed by CPR for civil rights actions not accepted by the P&A.

(4) Challenges to the adequacy of the investigation should be initiated whenever warranted. Possible avenues to pursue include:

   a. appealing the investigation pursuant to the regulations

   b. requesting a new investigation by either EOHS or the DPPC

   c. conducting an independent P&A investigation

(5) The Center for Public Representation will be responsible for conducting a periodic analysis of both the data and investigations to evaluate the existence of patterns and practices.

(6) CPR will be responsible for determining whether a project to remedy any pattern of neglect is appropriate.

IV. LIFE LINE:

Affirmative or preventative actions are necessary to avoid the P&A adoption of a passive, reactive role with respect to client deaths at inpatient facilities. In response to this, we have decided to establish a 24 hour hot-line or life line for families or concerned persons to call to report emergencies in which an individual is seriously at risk of death. Although CPR will assume much of the responsibility for this initiative, its success is dependent upon the unfaltering cooperation of the local offices. The project will include the following components:

1. a twenty-four hour number will be publicized statewide. CPR will be responsible for all contacts from family members and/or concerned persons. If appropriate, CPR will obtain a release of information. All initial determinations about whether a report constitutes an emergency will be made by CPR.

2. CPR will immediately contact the advocate or attorney, who must see the client within twenty-four hours.

3. The advocate or attorney will report to CPR within twenty-four hours about the client's status and whether he/she was able to secure medical or other assistance from the hospital.

4. CPR will contact the hospital or DMH Central Office, if local office interventions have been unsuccessful.

5. CPR is responsible for providing the original contact with a status report. It will be mutually decided whether it is appropriate to pursue any further action.

6. In exceptional cases, with the permission of either the client or guardian, CPR will notify the media. CPR will assist families in contacting the media if the resident is incompetent and/or incapacitated and if there is no guardian.

7. The advocate will open a case on the affected individual when appropriate.

Please review this and contact me by February 17, 1988 if you have any comments or concerns.

Senator **Harkin**. Lastly, we recognize Ms. Reneé Bostick, President of the National Association for Rights Protection and Advocacy. Reneé, welcome to the Subcommittee. Please proceed.

Ms. **Bostick**. Thank you, Senator Harkin.

The difficulty with being last on such an incredible panel is that no matter how long I do this type of work, I am always overwhelmed by the stories that I hear.

I am currently the President of the National Association for Rights Protection and Advocacy, and for the past 9 years, I have been the Mental Health Unit Chief at Ohio Legal Rights Service. About six week ago, I moved to Michigan—and am considered somewhat of a turncoat because of the rivalry between Ohio and Michigan. I moved to Michigan to assume the position of Director of the Division of Mental Health Advocacy Services.

My comments are based on those experiences as well as the fact that I am a consumer. I spent a year and a half of my life in an institution becoming personally familiar with abuses of the current psychiatric system.

The purpose of my comments today are to again, as many members of this panel have, try to focus on the issues confronting the P&A. Abuse and neglect is alive and well in psychiatric hospitals across the country. The mission of the P&A is to represent the expressed wishes of persons labelled mentally ill, and is a fundamental step toward the elimination of abuse and neglect and the empowerment of individuals who are labelled mentally ill.

I want to begin by discussing a few cases which highlight and exemplify the abuses of the mental health system. I have to confess that I was reluctant to begin with situation that could appear to sensationalize what goes on in the system. However, such conditions do exist and it is important that the Committee be aware of these problems.

And finally, I want to urge the reauthorization of the P&A Act.

As I said, six week ago when I moved to Michigan, I found problems that mirror the problems I had found in Ohio and problems which further underscore the need for an effective P&A system.

I also came upon some hard realities, probably more difficult realities than we had encountered in Ohio. First, the numbers of clients and their problems for outstrip the present capacity of the P&A system, especially in longer states like Michigan. When I testified before the House subcommittee, I was asked by Representative Walgren what our advocate-to-institutionalized person ratio was in the State of Michigan. After some research, I was able to determine that our current P&A system supports one advocate to 2,567 individuals in facilities.

I have a letter to Representative Walgren documenting this fact that I would like to include in the record.

In large States, there are also additional geographic barriers that I think are worthy of recognition. Although smaller states can be more readily available to clients, such as Massachusetts where Mr. Schwartz mentioned that his staff are available on a 24-hour basis. In Michigan, our availability is impaired by the fact that it is as far for an advocate to drive from Detroit to Newbury Regional Children's Psychiatric Hospital in the Upper Peninsula, as it is to drive from Detroit here to Washington, D.C. It is an 8- to 10-hour drive. The geographic area for which we are responsible is enormous.

Michigan's 17 public psychiatric hospitals are spread out across the state.

But let me speak to one example of the problems that we are facing. In my third week in Michigan, I received a call from a member of the Mental Health Advocacy Services Division advisory council who wanted to know if the P&A was currently investigating a recent death of a person from Northville Regional Psychiatric Center. This Center has been sued by the Justice Department, and was one of the thirty one facilities investigated in 1985 by staff for this subcommittee in its investigation of the "Care of Institutionalized Mentally Disabled Persons." It is the largest psychiatric hospital I have ever seen. It is 850 beds. That sounds small in relation to what Mr. Schwartz was talking about, but let me assure you that the problems there are enormous.

We began investigating this situation when a client's body was discovered in a field near the hospital 13 days after he was reported as missing from the hospital. His body had began to decompose, and his face had been eaten by animals. The client was reportedly forcibly medicated, restrained, and secluded on the day he was thought to have escaped from the hospital. His disappearance was not reported to police for 3 days, allegedly because of staff shortages and shift changes. The cause of death was listed as hypothermia.

Many questions obviously surround this man's death, Questions which the P&A has not been able to confirm or refute—Questions raised by the media as to whether or not the individual received a lethal dose of psychotropic medication and was then dumped in a nearby field.

We have not been able to do investigation in this particular case because the Department of Mental Health has their internal advocacy department taking a look at this situation and will not release any information about the client or records of this individual until they complete their internal investigation.

I think this case underscores the need for more stringent legislation on the issue of access.

To juxtapose the current Federal law on access with Ohio law reveals a substantial difference in authority and therefore ability to conduct such investigations. Ohio law grants the P&A statutory access to both the individual and to their records. With such authority the Michigan P&A could now be investigating this man's death, rather than waiting for DMH's conclusions.

During my work in Ohio, I met an individual four years ago who, for purposes of the testimony, I will refer to as Mr. Short. He, probably more than any other individual that I have ever represented, left a poignant mark on my heart.

When I met him, he was in a seclusion room, in four-point restraints, a body posey, face mask, and mitts. When I questioned staff about when he was last released, they could not remember the last time he was out of restraints. Allegedly, it was because of his self-injurious behavior. Mr. Short swallowed glass, nails, tacks, a variety of things that required more than 30 surgeries, and at the time his current physician was suggesting a lobotomy.

When I got access to his record, I found out he was a 34 year-old individual who had been institutionalized since the age of 7. He had spent 20 years of his life in a mental retardation facility, even though there was no evidence in his record that he was mentally retarded. The seven years he had spent in a psychiatric hospital.

When I talked with him, I found out that more than anything else, he wanted out of the hospital, he wanted to live in the community like other individuals, and he was an individual who was deeply saddened by a life where he had no control or no choice.

My conversation with his doctor confirmed his helplessness and the doctor's unwillingness to even listen to her client. The doctor, who had received no medical training in the United States, insisted that she and only she would decide this man's fate.

I am convinced that without an advocate's intervention and without our ability to be able to threaten litigation, Mr. Short would still, 4 years later, be living in that seclusion room. Through the efforts of an advocate, he was not only released from seclusion, but also later from the facility.

I also want to mention two systemic efforts that we undertook in Ohio that were aided by the access state law provided. After representing countless individuals like Mr. Short, the P&D observed countless problems with restraint and seclusion. As a result, we conducted a survey of restraint and seclusion practices across the State of Ohio. The findings model many of the 1985 findings of the Senate Subcommittee. With those findings, the P&A was able to persuade the Department of Mental Health to review and revise its seclusion and restraint rule.

Unfortunately, the desired outcome did not occur as a result of our systemic efforts at the Central Ohio Psychiatric Hospital. We spent two years of investigation and negotiation with the Department of Mental Health which failed to have any substantive impact on the abusive practices of the institution. Last year, the P&A filed a Federal class action lawsuit in order to protect and advocate the rights of individuals held in that facility. The suit alleged that the use of excessive restraint, seclusion, and medication, as well as a lack of treatment and discharge planning. As a result of our access to individuals living in institutions, the P&A became aware of, sought to correct and finally litigated those rights violations.

As I said in the beginning, even through the problems that P&As are charged to address, abuse and neglect, still remain. The P&As have began to effect the balance of power by representing the wishes of our clients. Debates are likely to continue about the role and priorities of the P&A, but not about the need for the reauthorizaiton and expansion of the P&A system.

NARPA and other organizations firmly believe that respecting and representing the wishes of persons labelled mentally ill is the first and fundamental step to eliminate abuse and neglect and to empower such individuals.

Thank you for the opportunity to testify.

Senator HARKIN. Thank you very much, Ms. Bostick.

[The prepared statement of Ms. Bostick and a statement to the House Subcommittee on Health and the Environment given on April 25 follow:]

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TESTIMONY OF

M. RENEE' BOSTICK
PRESIDENT
NATIONAL ASSOCIATION FOR RIGHTS PROTECTION AND ADVOCACY

SENATE SUBCOMMITTEE ON THE HANDICAPPED

OF THE

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

May 10, 1988

INTRODUCTION

Good Afternoon. I am M. Renee' Bostick and I am the President of the National Association for Rights Protection and Advocacy. I would like to thank Senator Tom Harkin and members of the Subcommittee on the Handicapped for this opportunity to present testimony supporting the reauthorization of the "Protection and Advocacy for Mentally Ill Persons Act of 1986," P.L. 99-319.

Let me begin by sharing some of my background, which is the basis for many of my comments today. Currently, I am in my third term as President of the National Association for Rights Protection and Advocacy. NARPA is the only national advocacy organization whose diverse membership includes attorneys, advocates, ex-patients, as well as mental health employees and directors. NARPA was formed in 1981 and is dedicated to the empowerment of persons labelled mentally ill and persons with developmental disabilities.

In addition to my role as President of NARPA, I served as Chief of the Mental Health Unit of the Ohio Legal Rights Service for the past nine years. OLRS has been protecting and advocating for the rights of persons labelled mentally ill since 1976 pursuant to state statute. In 1981, OLRS became the Protection and Advocacy Agency for persons with developmental disabilities, and assumed responsibility as the P&A for persons labelled mentally ill upon the passage of P.L. 99-319 in 1986.

A month ago I went to the Michigan Protection and Advocacy Service as the Director of their Protection and Advocacy services for people who are labelled mentally ill.

It is important for me to mention that my comments also come from my personal experiences as a consumer of mental health services. More than a year and a half of my life was spent becoming personally familiar with the abuses within the mental health system.

Thus my comments today are based on my personal experience, my past nine years of involvement with two large P&A programs, and my leadership role with a national advocacy organization committed to rights protection and advocacy work.

The purpose of my testimony today is twofold. First, I want to discuss the importance of the current protection and advocacy system for persons labelled mentally ill. Second, I want to urge the reauthorization of the "Protection and Advocacy for Mentally Ill Persons Act." Two years after the passage of P.L. 99-319, substantial gains have been made by the P&A system on behalf of these individuals. However, to fully implement the purpose of this Act, NARPA as part of a coalition of other advocacy organizations has made a number of recommendations to this Subcommittee. NARPA urges adoption of these recommendations, most importantly changes in the P&A's statutory authority for access to records, and increases in the authorization level.

CLIENTS' WISHES PARAMOUNT

The most important value of the P&A system is providing a voice for persons who have historically been silenced by the system responsible for their care. Although the three organizations that I have had the opportunity to become involved with (NARPA, OLRS, and MPAS) are very different, they all have one important theme in common. All three are dedicated to representing the expressed wishes of persons who have been labelled mentally ill. The P&A system is the only national system advocating for persons labelled mentally ill which is founded upon the mission of respecting and responding to the preferences of their clients. Despite debates about the P&A's role and priorities, representations of clients wishes is a fundamental and essential step in empowerment of people labelled mentally ill. To change the perception of treatment of persons labeled mentally ill, it is essential that such persons be given an voice in and control of their own lives.

VALUE OF THE P&A SYSTEM

The true test of this mission and of the value of the protection and advocacy system becomes apparent when you examine the impact of the system on the individual lives of clients. While at the Ohio Legal Rights Service, I had the opportunity to work with countless individuals, but one individual left an indelible mark on my life. For purposes of this testimony, I will refer to him as Mr. Short. Mr. Short taught me more about the role of an advocate than any advocacy training or legislative mandate ever could.

I first met Mr. Short four years ago when I was monitoring a large state psychiatric hospital in Ohio. I found him lying in a dark barren seclusion room in four point leather restraints,

which involves tying a person spread-eagled by the ankles and wrists, a body posey, which is a restraint to tie a persons' trunk down to the bed, a face mask, and restraint mittens. When I queried staff as to how long he had been in this condition they could not remember when he was last released for any period of time. He was confined to that room and tied to that bed as a result of reports of self-injurious behavior. The most dangerous of this behavior involved Mr. Short ingesting objects which the hospital left within his reach, such as broken glass, tacks, pins, nails, spoons, etc. The nurse informed me that he had over thirty surgeries to remove these items, and that his surgeon was currently suggesting a lobotomy.

Upon inspection of his record, I discovered that Mr. Short, who was 34 years old, had been institutionalized since the age of 7. He had spent 20 years in the state center for mental retardation despite evidence which suggested he was not mentally retarded. Seven years before I met him, he had been transferred by court order to the psychiatric hospital.

I requested to enter his seclusion room to talk with him and requested that some of his restraints, such as the face mask and the mittens, be removed while I talked with him. One might expect to find an individual who would have some difficulty communicating, and who would be confused or hostile given his circumstances. Instead I found an individual who was articulate, calm, and deeply saddened by a life over which he lacked all control. I talked with Mr. Short about his concerns. He wanted to get out of restraints, to return to the center for mental retardation, and eventually to live in the community. When I left Mr. Short in the seclusion room I spoke with his doctor and asked her what kind of behavior Mr. Short had to exhibit in order to be released from the restraints. His doctor, who had not received any of her medical training in the United States, informed me that she was the doctor, that she and only she would determine when he would be released, and she would not tell me what Mr. Short would have to do to be released.

However, as the result of involvement by an advocate, within a few weeks Mr. Short was removed from restraints, and in the following months was returned to the mental retardation center. I was able to form a wonderfully close relationship with Mr. Short and began to discover that his self-injurious behavior was his only mechanism to express his desire to be released from the institution he hated so much. Each time he swallowed he was sent to a hospital and released from the psychiatric institution. Certainly this behavior would appear crazy to an outsider. However, much of what goes on in psychiatric hospitals would appear crazy to an outsider. Mr. Short's behavior was in fact largely a product of his 27 years of institutionalization.

According to the doctor and hospital Mr. Short was getting the treatment he deserved--fully restrained in an isolated dark barren seclusion room. It took an advocate to discover Mr. Short; it took an advocate to intercede with the mental health system for Mr. Short. Without the assistance of an advocate, I am sure that Mr. Short would have spent the last four years in that same dark, barren seclusion room in four point restraints, a body posey, face mask and restraint mittens.

Representing Mr. Short and countless other individuals who were subjected to the excessive and inappropriate use of seclusion and restraints led OLRS to undertake systemic work in this area. Following two years of investigation and negotiation, OLRS filed a federal class action lawsuit on behalf of residents of the Central Ohio Psychiatric Hospital alleging excessive and punitive use of restraint and seclusion, excessive and inappropriate use of medication, lack of treatment planning and implementation, and lack of discharge planning. This case is still pending.

Also individual clients led OLRS to conduct a review of restraint and seclusion practices in seven of the seventeen state institutions in Ohio during the spring of 1987. The results of the study were alarming, and clearly indicated the need for change in Ohio's restraint and seclusion administrative rules. OLRS staff found that clients were not exercised as required by the rule; that few if any prior interventions were used prior to restraint or seclusion; that individuals were restrained and secluded merely on a telephone order from a doctor, rather than after examination and personal authorization; that treatment plans listed restraint and seclusion as a mode of treatment, rather than an emergency intervention as required by the rule; and that often restraint and seclusion was used in conjunction with forced medication. As a result of our survey, the Department is reviewing and revising its rule on restraint and seclusion. Hopefully this effort will also cause a renewed Departmental effort to enforce the new rule as well.

Although I only came to the Michigan Protection and Advocacy Service a month ago, I have found numerous cases which underscore the need for protection and advocacy for persons labelled mentally ill. The following two examples illustrate the work of the P&A staff.

The first is the case of a 37 year old woman who had been petitioned in the state hospital by her neighbors. She had no previous psychiatric hospitalizations and did not appear to meet the statutory requirements for involuntary hospitalization. The neighbors' petition and the doctors' certificate stated that the rationale for involuntary hospitalization was that "she talks to her cats at night, her yard is full of weeds, she uses shocking language, and knocks on her neighbors' doors." Despite the fact that nothing in the petition described behavior which posed a danger to herself or others, and that the hospital failed to hold a meeting as required by statute to seek alternatives to hospitalization, she was committed to the hospital for 60 days.

She contacted the Michigan P&A and a writ of habeas corpus was filed on her behalf. The hospital released the client within three hours of receiving the writ, even though there had been no previous plans for discharge. Unfortunately, this occurred only after she had spent a month and a half in the psychiatric hospital against her will. Yet, without an advocate's intervention, her anger would have mounted and her needless hospitalization would have continued.

The second case involves a Jewish man who called from a Michigan psychiatric hospital to complain about infringements on his religious freedom. The hospital only offered Christian services and refused to offer or assist individuals in gaining access to Jewish services. The P&A and this man worked together to provide the man access to Jewish services as well as to change the state policy to require hospitals to provide religious services for all denominations so that all residents in hospitals have the opportunity to practice their beliefs.

ROLE OF ADVISORY COUNCIL

These examples illustrate the fact that representing clients' wishes has a dramatic impact, not only on the lives of individual clients, but on the system which is supposed to provide treatment to them. Consumer input also has a tremendous impact on the P&A system. The Advisory Council to the Mental Health P&A in Michigan has played an important role in helping to shape the program from its very beginning. Of the seventeen members of our Advisory Council, twelve are consumers, three are family members of individuals labelled mentally ill, and the remaining two are both consumers and family members. Additionally, the P&A governing board has three consumer members and the P&A has three staff members who are family member and five members who are consumers.

The Advisory Council has also played an important role in helping to shape the advocacy efforts by the mental health P&A. We hired an intake coordinator to supplement our information and referral staff at their suggestion. More recently, the Advisory Council expressed concern that the four public hearings we had scheduled to get public input into our priority setting process did not include any hearings in institutional settings. At the

Advisory Council's suggestion, we are scheduling an additional four public hearings in psychiatric hospitals throughout the state.

The Michigan P&A has made a significant investment in the involvement and training of persons labeled mentally ill. Michigan P&A sponsored the 1987 NARPA conference and through a combination of external fund raising and internal contributions spent close to $20,000 on consumer scholarships for the conference. The agency also sponsored three consumers to the 1987 consumers' Alternatives Conference in West Virginia, an expenditure of over $1,000. The P&A also got one of these individuals out of the hospital to attend the conference. An advisory board member was sponsored at the P&A training in St. Louis in January, 1987, which cost about $800. A $500 contribution was made to the Pathways to Employment conference for consumer scholarships. In the last year, Michigan P&A has spent approximately $5,000 to support the Advisory Board's monthly meetings. This includes all expenses for consumers across the state to attend those meetings. The Board of Directors have donated their time and energies. The only expense for this group in the last year was for an appreciation luncheon costing $300. Close to $30,000 of Michigan P&A's 1987 authorization was invested in individuals and mechanisms to facilitate their active participation.

The Michigan P&A has also initiated a planning process for establishing ongoing priorities for the coming fiscal year. Out early attempts to identify factors which impact on or give input to our planning process resulted in the following list: Advisory

Council, Board of Directors, public hearings, external evaluations, P&A peer review process, client satisfaction surveys, client grievances, P&A federal and state mandates, case management, case statistics, case audits, staff input of experiences and client involvement in P&A committees of task forces. All of these sources impact on the priority process.

NEED FOR REAUTHORIZATION AND RESTRUCTURING

The question before this Subcommittee should not be whether or not to reauthorize this Act, since the continuing need for advocacy in psychiatric institutions is painfully clear. The question is how much of a commitment is Congress willing to make to ensure that the rights of individuals labelled mentally ill are protected.

However, I would like to focus on two other areas in which change is needed. The first has to do with access to records, and the second with funding levels.

My experience advocating for people labelled mentally ill in Michigan already differs greatly from my experience in Ohio, and one of the chief reasons has to do with access to client records. By state statute OLRS has access to all clients' records, which enabled OLRS to undertake systemic advocacy efforts, such as the efforts to revise the seclusion and restraint rule, and investigations for the lawsuit I mentioned earlier.. Such access would have also permitted a prompt investigation of the following situation in Michigan.

In my third week at the Michigan P&A, I conducted a site visit at the largest psychiatric hospital in the state. The visit was prompted by a call from a member of the Advisory Council who questioned if the P&A was investigating the recent death of a resident at Northville Psychiatric Hospital. The client's body was discovered in a nearby field thirteen days after he was reported missing from the hospital. His body was decomposed and his face had been eaten by animals. The client was forcibly medicated, restrained, and secluded on the day he supposedly escaped from the hospital. His disappearance was not reported to the police for three days, allegedly because of staffing shortages and shift changes. The cause of death was listed as hypothermia.

Many questions surround this man's death. The press has questioned whether he might have accidentally been given a lethal injection of psychotropic medication, then dumped in the field to cover up. The fact that animals only preyed on his face suggests that he might have had fresh facial injuries. Unfortunately, the P&A can neither confirm nor refute these allegations since the Department of Mental Health has refused to give us access to any information with regard to this client, including his records. This underscores the coalition's recommendation that P&As need broad access, particulary the right of access to records of residents who die in the care of psychiatric hospitals.

NARPA also urges the Subcommittee to adopt the Coalition's recommended authorization levels, which would mirror the allocation for the P&A system for persons with developmental disabilities. NARPA strongly supports the Coalition's statement that "it is apparent that even with no changes in the law, the funding levels currently authorized are inadequate to enable P&As

to fully protect mentally ill people against abuse and neglect in residential facilities." The examples that I discussed today and the work of the current P&A system are only the tip of the iceberg. Thousands of individuals are still suffering the gross abuse and neglect which caused the Senate Subcommittee on the Handicapped to initiate efforts to enact P.L. 99-316.

The need for additional funding for the P&A system was never so clear to me as during my review of Northville hospital where the man I discussed previously had died. I was overwhelmed by the problems and inhumane conditions evident in this 850 bed facility: building after building of people cramped into small spaces; staff so outnumbered that they huddled together in the nursing station; residents so drugged that they slept on the hallway floors outside their locked bedrooms. Some "bedrooms" consisted of large open rooms with fourteen to sixteen beds. Clothes were locked away in a massive room with large wooden bins. Bathrooms consisted of a line of toilets, some without doors. The door to the bathroom was propped open. Seclusion rooms stank of urine and leather restraints lay waiting tied to metal bed frames. There were no signs of privacy, individuality or dignity. Clients' most frequent request was, "I want out." Unfortunately, it takes so long to go through the discharge process that frustrated clients "act out" and get removed from the discharge list. Thus, their lives become a chronic cycle of frustrated attempts to get out. Without increased authorization levels, there is little we can do to investigate, much less prevent abuses like these at facilities across the country.

In my testimony today, I have attempted to inform the Subcommittee of the accomplishments and limitations of the P&A system. P&As across the country quickly and effectively assumed the monumental mandate of protecting and advocating for persons labelled mentally ill. Debates will continue about the role and priorities of the P&A system. However, in a client-driven advocacy system, the job of advocates is to respect and to represent the preferences of our clients. This is fundamental to empower persons labelled mentally ill.

The 1978 Report to the President from the President's Commission on Mental Health stated:

> We are keenly aware that even the best intentioned efforts to deliver services to mentally disabled persons have historically resulted in well documented cases of abuse and neglect. For this reason an effective advocacy system must be created to protect the rights of all who receive services.

This statement is more important today than it was ten years ago because we now have the opportunity before us to alter the treatment of persons labelled mentally ill through an effective advocacy system which represents the wishes of persons labelled mentally ill. As Saul Alinsky said:

> We learn when we respect the dignity of people that they cannot be denied the elementary right to participate fully in the solution of their own problems. Denial of the opportunity for participation is the denial of human dignity and democracy.

The challenge before the Subcommittee today is to ensure that persons labelled mentally ill are no longer denied their dignity or democracy.

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May 5, 1988

Representative Doug Walgren
House Subcommittee on Health and the Environment
2415 Rayburn House Office Bldg.
Washington, D.C. 20515

Dear Representative Walgren:

On behalf of the National Association for Rights Protection and Advocacy, I would like to thank you for the opportunity to present testimony before the House Subcommittee on Health and the Environment on April 25 supporting the reauthorization of the "Protection and Advocacy for Mentally Ill Individuals Act of 1986" P.L. 99-319. Following my testimony which included a recommendation to increase authorization levels for the P&A system, you requested information on the advocate to institutionalized persons ratio in Michigan.

Michigan's current authorization level under P.L. 99-319 affords the following P&A advocate to institutionalized person ratio: one advocate to 788 individuals in state hospitals, one advocate to 518 individuals in private hospitals, and one advocate to 1,260 individuals in licensed residential facilities. The overall advocate to institionalized person ratio is an astounding 1/2,567 (see attachment).

However, these numbers only tell a part of the story, in large states such as Michigan the enormous geographic distance presents another barrier for P&A agencies. It is as far for an advocate to drive from Detroit to the Newberry Regional Psychiatric Hospital in the Upper Pennisula of Michigan, as it is to drive from Detroit to Washington D.C. The distance has a negative impact on P&A services in several ways, including but not limited to problems with client outreach, with obtaining effective client input into the system and priorities and with case representation.

Current authorization levels are insufficient for P&A agencies to effectively protect and advocate the rights of persons labelled mentally ill. The magnitude of the client population and the geographic distance are but two factors which speak to the need to increase authorization levels. The most important factor, however, is the Congressional finding that persons labelled mentally ill are vulnerable to abuse and neglect. P.L. 99-319 established a broad, but essential mission for P&A agencies of protecting and advocating rights. If Congress truely intends P&A agencies to act upon that mission, then authorization levels must be commensurate with the mandate.

Respectfully,
M. Renee Bostick
M. Renee' Bostick, President

Enclosure

cc: Rep. Henry Waxman, Chair

Michigan Protection and Advocacy Service
Division of Mental Health Advocacy

ADVOCATE TO INSTITUTIONALIZED PERSON RATIO

Type of Facility	Population	Advocate[4] /Inst. Person Ratio
State Hospital	4,726[1]	1/788
Private Hospital	3,106[2]	1/518
Licensed Residential Facility	7,569[3]	1/1,260
TOTAL	15,401	1/2,567

[1] Book Census reported by Director's Office Michigan Department of Mental Health, as of January 31, 1988.

[2] Number of licensed psychiatric hospital beds as reported by Sharon Hunt, Office of Licensing, Monitoring and Accreditation, Michigan Department of Mental Health, as of April 1, 1988.

[3] Estimated number of licensed residential beds for persons labelled mentally ill. Figure based upon information reported by Joe Schwinger, Division of Adult Foster Care Licensing, Bureau of Regulatory Services, Michigan Department of Social Services. Currently, DSS reports 30,236 persons in 4,260 licensure residential facilities. These facilities serve persons labelled mentally ill, with developmental disabilities, who are physically disabled or elderly. Since DSS does not keep statistics on how many beds serve persons from each of these groups and since there are four major groups of persons served by licensed residential facility, the estimated figure was a result of dividing the total population in these facilities by four. DSS reported figures were current through March 31, 1988.

[4] The current PAMI authorization level for the Michigan Protection and Advocacy Services is $302,316. Six advocates are employed with federal monies to carry out the broad mandates of P.L. 99-319.

Senator HARKIN. Everyone here today in their written testimony and most in their spoken testimony talked about the need to have access to records, both for those who are still living and those who are deceased. But in the present law, it states that the system is established in a State to protect and advocate the rights of all mentally ill individuals "shall have access to all records of any individual who is a client of the system if such individual or the legal guardian, conservator, or other legal representative of such individual has authorized the system to have such access and any individual who, by reason of the mental or physical condition of such individual, is unable to authorize the system to have such access, who does not have a legal guardian, conservator, or other legal representative, or for whom the legal guardian is the State, and with respect to whom a complaint has been received by the system, or with respect to whom there is probable cause to believe that such individual has been subject to abuse or neglect."

Now, why doesn't that cover it? Everyone has testified to the need to get access to records, and it is in the law. What's wrong? What is lacking?

Mr. Schwartz, what is lacking?

Mr. SCHWARTZ. Senator, I think that the original bill made a significant amount of progress from where we all were before a P&A was established, and it did go far in solving this problem.

There are two pieces that have been left. In at least my experience in most of the States that I have visited, they have identified individuals who are not capable of asking for assistance as not being clients. They are not a client. You can't go and see them. I mean, the access to the places in many ways—I think you are referring to the section on access to records and access to places—the access to the people themselves is the biggest problem that I think we have, even bigger than the records.

Senator HARKIN. Let me read this. It says, "shall have access"—"P&As shall have access to all records of any individual who is a client of the system or who is unable to authorize the system to have access, does not have a legal guardian or other representative, and with respect to whom a complaint has been received or with respect to a person who has probable cause, where there is probable cause to believe that such individual"—so it would seem to me that if you are an advocate, you are an attorney, you go into Worcester State Hospital, and either through observation, through reporting by other individuals or some such means, you come upon an individual who you believe has been abused or neglected, and you ask to see the records—well, if that person has a legal guardian or conservator, then it would seem to me that you could go to that legal guardian or conservator. If they don't have a legal guardian or conservator, and you have probable cause to believe that they are subject to abuse and neglect, it seems to me that you have access to records.

Mr. SCHWARTZ. There is no dispute with the language, but the original assumption that you are making in that example is the place where there is a problem.

Let me say in Massachusetts we don't have a problem. The State has essentially agreed to let advocates be there on the wards of the hospitals without restrictions. That is not true in New Mexico, it is not true in Georgia, and it is not true in a number of States, because the original assumption is we go on the wards, and the fact is you can't get on the wards in a number of places if the individual hasn't asked for your assistance.

I was in Georgia at this particular Milledgeville State Hospital that I mentioned, a very large facility, and access to records is not access to people. And so when we went to go on the ward, this was a ward of people who had been institutionalized a minimum of ten years; there was no one who had been there less than ten years. Many of the people on that ward had dual disabilities. They were also retarded. There was another ward next to it where people were all over 65, with an average length of stay of 25 years. Those individuals, no matter what information you give them, are not going to regularly call the protection and advocacy agency.

So we can't go there and see the probable cause in the first place. The probable cause that I would worry about is, is it possible that a man or a woman so vulnerable and so institutionalized might have a problem that I have to go and ask them about. That is what I do with an elderly grandparent. I don't wait until they call me. I know that their ability to call me and ask for something extra that they need is very limited.

So the situation that we all face is large institutions where people have been confined, and we need to go to them, and the statute needs to ensure that the whole system isn't driven as it is, I think, to some extent now by the language of the bill, by complaints.

To me, the biggest problem that I found as a consultant in the States was that everyone, even the P&As, felt that the language of the bill said "if a complaint is received"—and so they waited for people to complain; or they were concerned that they had limited authorization. And I am saying that there are a lot of people who have complaints in their hearts who cannot articulate those complaints, or don't even know that they have rights. And we need to have the ability—and we don't have the ability in Georgia, and we don't have it in New Mexico where I was, and we didn't have it in Washington State—to go on those wards.

Senator HARKIN. You are telling me that a State that has established a P&A system under this law—all States have that now—that these protection and advocacy individuals do not have the right to go on the wards?

Mr. SCHWARTZ. That's right. And what I am saying is that to be——

Senator HARKIN. Well, that's access to records, though.

Mr. SCHWARTZ. Right.

Senator HARKIN. To have access to records, you have got to have probable cause. Do you mean to say you can't just go and visit wards?

Mr. SCHWARTZ. That's right, that's right. Let me say that that is different in every State. Some State agencies have been cooperative. In my State of Massachusetts and in the neighboring State of Rhode Island, they do allow unrestricted access. But I think the Subcommittee should be aware that when I met with each of the superintendents of the State hospitals in Georgia, they informed me in no uncertain terms that P&A advocates would only be allowed on if a client asked for their assistance. And I said, well, what do you do for the folks who can't talk? And they said, well, it would be a violation of their confidentiality if we allowed a P&A advocate on the ward to go reach out to them.

I said, well, all I want to do is go and ask: Do you want help? If the person says no, our programs are designed to respect people's wishes.

And the superintended said no, no, no; that would be a violation of their confidentiality.

The Subcommittee should be aware that there is nothing in the bill, in the original bill or in any proposed amendments, that allows access to individuals who cannot request assistance. Instead, there is an inference to the contrary, because the bill speaks in terms of complaints about abuse.

Senator HARKIN. What would happen in a State—you mentioned a couple of States, and I don't know them all that well and how they operate—but let's say you wanted to go on a ward and visit people—the very thing you were just talking about—and ask them if they wanted help. And you use as the basis of probable cause the fact that there had been some allegations made privately or publicly to you that people were being abused or neglected on a ward. Would the hospital or the home recognize that? I mean, what would your recourse be?

Mr. SCHWARTZ. In the States that I have seen these problems—and they represent about half of the ones I have been to—the answer is no.

Senator HARKIN. Then, what would you do? Let's say you had reason to believe—let's say someone came to you and said, "I know of something bad going on in there", and you went to the hospital and you said, "I'd like to go on the ward and talk to some people", and they said, "No, you can't do it".

What would you do? What would be your recourse? What would you do as an attorney. Would you get a court order?

Mr. SCHWARTZ. I would do two things. First of all, I think there are certain sort of strategies that advocates can learn to use. One of them that I do is that I try to find attendants, I try to find staff people who can give me the information that would give rise to clear probable cause or who would actually have a referral to my office. And in fact, over some years, that is one strategy that has worked.

Another is that I try to find someone else on the ward who is capable of speaking, who asks me to come out and see them, and while I am there, I then will spend some time with that person.

But yes, Senator, I think that if I am denied total access to the ward, as the advocates have been in some States, the strategy would be to bring some legal action.

In New Mexico, where they have considered that, they are very concerned that the statute does not provide them a basis to be able to sue in behalf of the clients who have not asked for their assistance.

The issue of records and access to records to me is really focused or limited to clients who have died. There are States who have taken the position that clients who have now died are not clients of the system; that the P&As don't deserve those records.

Senator HARKIN. We talked about that, and I think we can do something about that.

Ms. BOSTICK. Senator, if I could, on that particular question, I'd like to add——

Senator HARKIN. Yes, before you do, as I said, both Senator Weicker and I are on the authorizing committee, on the Appropriations Committee, and right now down the hall, we are meeting on what we call our 302(b) allocations, which is to say that all of us who chair subcommittees on the Appropriations Committee have got to be there to fight for money. And I want to go down there and fight for the money that we need for these programs, so I am going to have to excuse myself. I am ten minutes late, and I don't want to be there too late.

So what I am going to do is turn over the Subcommittee to Mr. Silverstein, who can go ahead and take testimony, ask questions, fill the record, and adjourn the Subcommittee when he wants to.

So I apologize, but I just want to make it clear why I have to leave.

Ms. BOSTICK. I would prefer that you go advocate for money.

Senator HARKIN. I will. And I will leave this to Mr. Silverstein. Thank you all very much for being here.

[Whereupon, Mr. Silverstein assumed the Chair.]

Ms. BOSTICK. If I could, I just want to add two other points on the issue of access to clients and records. One has to do with a problem that is posed for P&As where individuals have guardians. Potentially, some individuals may have complaints against their guardian. It makes it very difficult for the P&A to gain access to an individual's record if the facility will only honor the signature of the guardian.

So, another area of conflict exists when P&A's represent a individual who has a conflict with his or her guardian.

One other area of conflict has to do with anonymous complaints. In Michigan, we have received several anonymous complaints, and when we attempt to contact the client first, or if that individual has been discharged from the facility, the facility typically refuses to allow us to then contact the individual. This prevents us from determining whether the individual had or still has a problem with his or her treatment. Further, we have no assurance that the individual is even made aware of the P&As services.

Mr. SILVERSTEIN. One quick follow-up question related to the access issue.

Going back to the original declaration of purpose of the legislation, it talks about investigating incidents of abuse and neglect of mentally ill individuals "if the incidents are reported to the system or if there is probable cause to believe that the incidents occur".

Now, in the original passage of the legislation, there was a need to try to figure out a way of balancing on the one hand the problem of "fishing expeditions" and on the other hand, address the issue that you are raising, and this was the "compromise position" to address the issue.

I guess my question to you is, is it possible to clarify what constitutes probable cause, and by so doing, address some of the concerns that you are raising?

Mr. SCHWARTZ. I think as a practical matter, it is, and I would be happy to work with the Subcommittee in finding the appropriate language.

I guess my experience is such that when I go to wards of large institutions and see people who are there for very long periods of time, it at least triggers the possibility of probable cause for neglect. It doesn't necessarily equal that, but it at least raises that question. And that is not a kind of understanding that the States that have resisted access or have limited access would subscribe to.

Mr. SILVERSTEIN. I would request of all the witnesses, if you'd like, and the others who testified as well, some assistance in trying to clarify what is meant by "probable cause".

Mr. SCHWARTZ. The "fishing expedition" issue, which I know was of some concern in the beginning, just does not ring true in the experience—well, it doesn't ring true in two places. One is that the Committee should be aware that a significant number of States—and I am not sure exactly how many, but half of the 15 or 20 that I have seen—have granted unlimited access, have not tried to toy with all these fine distinctions. They have recognized of their own accord that disabled people and people who have severe handicaps are not in the position to request or complain. And there haven't been "fishing expeditions", and those States have not gone crazy, and there haven't been tons of lawsuits, and all the doctors aren't quitting, and some of the worst kinds of nightmares that you may have heard about have not occurred.

So the reality, we now have a documented history, and it is a good history.

Second, in those States where there have been restrictions on the access, I just don't think that people go into "fishing expeditions" or advocates are going, looking for trouble when we are talking about people who have been institutionalized for 20 or 30 years. I mean, these aren't folks who are waving banners and trying to find everybody in sight to sue.

We are talking about just getting some attention for people who don't have companions. We are talking about reaching out to them and asking them questions. And in some States, even in States that have set up screening mechanisms on this issue, there haven't been problems.

Mr. SILVERSTEIN. Lori, Senator Harkin wanted to ask you this question. You testified that, "The bottom line is that my father was healthy one week and dead the next, and people in responsible positions ignored their responsibilities to care for him and to protect his Constitutional rights." He just wanted to know why do you think that people are, in 1988, still doing this to other people?

In a previous panel, one possible explanation was the pay, the quality of the staff. Do you have any comments?

Ms. INCROPERA. I feel that the DMH, who works for the hospitals, is there totally to protect themselves and to make sure that their funding is going to support the institutions; and they are not there for the families at all.

I had been trying to ask for help many, many times and was totally denied any help. As far as the records go, Steve Schwartz had asked to see the records and was told he couldn't see them because I was the legal guardian. I became the legal guardian in September and was never notified until December that I was the legal guardian. I think they are doing this for, like you say, the lack of care—the people who are in these institutions who are taking care of these people are not responsible people.

There was one person on the floor who was an aide, taking care of my father who was an ex-convict, who had been charged with killing several people. I don't think those are qualified people to take care of the mentally ill in institutions.

Mr. SILVERSTEIN. Do any of the other panelists have any comments?

Ms. KOHN. I come from an area where there is an unemployment rate of 3.2 percent. The McDonald's stands are paying $7 an hour for kids to come and work there. The kinds of people who are willing to work at State hospitals, for wages that are far below that, are either people who are incredibly dedicated or are incredibly unable to get jobs at McDonald's. I think it is a serious situation.

I think the nursing shortage that has affected the Nation has also had a tremendous impact on the State hospital system. It is almost impossible to get appropriate, qualified nursing care to serve in the State hospital system.

Mr. SCHWARTZ. I think there is one other explanation, and that is when you put 3,000 people in one set of buildings, you are going to have problems, and 3,000 people who are vulnerable and handicapped, and expect anyone to even know their names is not real. So that the congregation of large numbers of disabled people in these big State hospitals is a recipe for abuse. It is easy for the Committee or for the American people to look at numbers and look at statistics, and there is a direct correlation between the number of people who are seriously abused and die in facilities and the size of those facilities; and there is another correlation between their age. You know that a person who is labelled as mentally ill and put in a State hospital has a virtual guarantee of dying at an age which is ten years lower than the national average. And it is not only staff, it is not only resources, although those are factors that contribute; it is also that there is no way of really relating to people individually and knowing them. And that is what makes large State hospitals particularly dangerous places.

Ms. BOSTICK. I concur with everyone else on the panel, but would just add that I think this legislation points to the fact that mentally ill individuals have been second-class citizens. We still segregate them. Individuals who get labelled mentally ill are not often deemed credible witnesses.

One of the most significant problems in Ohio in preventing or prosecuting abuse was the fact that once you are labelled mentally ill, you are no longer considered credible. Such individuals are accused of experiencing delusions or hallucinating or even of manipulating or lying when they report incidents of abuse.

The actions of institutional staff have gone unchecked. We know from history that the Justice Department, JCAHO and other organizations responsible for oversite have little to no impact. Institutional staff have learned they can abuse and neglect individuals and suffer no consequence.

I think this legislation may offer some hope of changing that.

Mr. SILVERSTEIN. Since the passage of this legislation, what is the major change in the behavior of State institution personnel or others that you work with in terms of the question of abuse and neglect?

In other words, are you noticing that this legislation is having or beginning to have a positive effect in accomplishing the goals of reducing and eliminating abuse and neglect?

Mr. SCHWARTZ. If I could answer that, and then we do need to take a plane back to Massachusetts, if we could be excused.

I'd like to answer that quickly in two ways. One is that the legislation and these programs are having a dramatic impact on the people who they are serving. And that needs to be said with the understanding of who they are not serving. We are making no impact on jails in Massachusetts; we are making no impact on nursing homes, on private psychiatric facilities, on community residences, on board and care homes, and on a litany of other 24-hour facilities. Nothing has changed there, or at least not as a result of this legislation.

We are making an impact, I think, on the State hospitals, because that is where we have targeted all of the resources.

The impact that we are making is for the individuals. We are serving 1,200 people; there are less people in State hospitals than there were when you passed this bill. There are more people with more services. There are less people being restrained, for less hours than when you passed this bill.

So for given individuals, of whom I have long lists of names, we have made a difference.

On the other hand, the hospitals in which we are working have a 100-year history. They have been around for a century; they are probably going to be around for a lot longer. We all contribute to them in some way or another, through our taxes or moral support. And we are not going to, I think, significantly change them in two years or five years or ten years.

When I was in Milledgeville, I told the half-time paralegal who was there, "You've got 3,000 people here. Take one ward." This hospital has been around 110 years. You take one year, at 15 people per ward, and spend a year on each ward. It will take you 30, 50 years before you get through the whole hospital. See this as a 50-year project to try to change this place. But do 15 people at a time." And with 15 people at a time, this one half-time person could make a difference.

Mr. SILVERSTEIN. Ms. Kohn, how about private institutions, nursing homes, hospitals, community facilities in Connecticut?

Ms. KOHN. Nothing has been touched. With the resources that we have had available, we have only been able to go into the one area, starting with the State hospital and moving out into the community only in terms of the advocacy kinds of programs in the community. We have not moved into nursing homes, boarding homes, anything beyond the State hospital.

Mr. SILVERSTEIN. Ms. Bostick.

Ms. BOSTICK. I think, as Mr. Schwartz said, I would agree that the P&A program has had dramatic impact on those individuals we have been able to reach. I think we have had impact in State hospitals but there is a lot of work left to do. I do not think that we have had the same amount of impact in other types of facilities.

NARPA was one of the organizations that very strongly advocated keeping the legislation focused on State institutions. First, because the authorization levels are not even adequate to serve people who are currently institutionalized. Second, the fact is that no one else to goes into psychiatric hospitals. Individuals who are in jails and prisons, although they do not receive adequate representation, at least receive some representation. There is no other organized body that is going into psychiatric hospitals to offer assistance to individuals.

[Additional material supplied for the record follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

Mr. Robert Silverstein
Subcommittee on the Handicapped
Senate Committee on Labor and
  Human Resources
Hart Office Building 113
Washington, D. C. 20510

Dear Mr. Silverstein:

Thank you for your willingness to include the enclosed Administration statement in the record of your May 10, 1988 hearing on reauthorization of the Protection and Advocacy for the Mentally Ill Individuals Act of 1986.

Sincerely yours,

Patricia Knight

Patricia Knight
Deputy Assistant Secretary
  for Legislation (Health)

Enclosure

Submission for the Record.

Senate Committee on Labor and Human Resources.

Subcommittee on the Handicapped.

Hearing on Protection and Advocacy.

May 10, 1988.

The Department of Health and Human Services is pleased to present this statement for the record concerning reauthorization of the Protection and Advocacy for Mentally Ill Individuals Act of 1986.

P.L. 99-319, the Protection and Advocacy for Mentally Ill Individuals act of 1986, was signed into law on May 23, 1986. Its intent is to provide formula grants allotments to State systems which have been established to ensure that the rights of mentally ill individuals are protected while they are inpatients or residents in facilities providing mental health care or treatment and for 90 days following discharge from such facilities.

At the time of enactment an existing program of Protection and Advocacy System (P&As) had already been established in each State to protect and advocate the rights of persons with developmental disabilities. In P.L. 99-319 the authority of these existing systems was expanded to include mental illness, in recognition of their experience and past accomplishments in investigating and resolving allegations of abuse and neglect in relation to the developmentally disabled populations. Funding for these programs is provided by an annual grant award to each existing P&A program, based upon a formula that considers both the population and relative per capita income of a State or Territory. P&A systems must be independent of any agency providing treatment or services (other than advocacy services) to mentally ill individuals.

The P&As provide independent advocacy services, including the investigation of reports of physical assaults; inappropriate or excessive use of medications, physical restraints, or isolation; failure to provide appropriate treatment; and failure to provide timely release and appropriate discharge planning. Over 9,700 mentally ill clients were served by P&A Systems in fiscal year 1987.

Although this program is principally conducted through the statewide P&A entities, section 115 of P.L. 99-319 requires the Secretary to provide technical assistance to the P&A Systems. Examples to date include through the following activities:

- Developed a two volume: Summary of Issues in Mental Health Law and National Consultant Resource Directory.
- Adapted National Center for State Courts "Guidelines for Involuntary Civil Commitment", for use by Protection and Advocacy Systems.
- Convened meeting of directors/coordinators from State P&A Program for the Mentally Ill to discuss administrative matters and other issues, such as access to records and

facilities, priority setting, and relationships between advisory and governing boards.

Furthermore, the program is in the process of:

- Developing education materials and a resource manual on "Strategies to Increase Primary Consumer and Family Involvement in Protection and Advocacy Systems."
- Developing education materials and a resource manual on "P&A Outreach to Black and Hispanic Mentally Ill Populations."
- Developing a Litigation Sourcebook for Protection and Advocacy Systems.
- Developing a plan and establishing a mechanism for a central computerized repository for legal briefs and other documents associated with mental health litigation to assist the legal staff of State P&A Systems in researching and preparing cases, and to serve as educational materials for new legal staff.

The Administration has proposed a 3-year renewal of the existing legislation. During this period, the P&A program will be phased over to the States. Other Federal funding totaling over $19 million for P&A activities will continue through the Administration on Developmental Disabilities of the Office of Human Development Services.

In summary, since P&A Systems are now established and operating in each State and Territory, the Administration is proposing a phase-over during the next three fiscal years, as the States continue these activities initiated and tested with Federal funds.

**The National Association of
Private
Psychiatric
Hospitals**

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Testimony Submitted by the

NATIONAL ASSOCIATION OF PRIVATE PSYCHIATRIC HOSPITALS

to the

Senate Committee on Labor and Human Resources
Subcommittee on the Handicapped

on the

Protection and Advocacy for Mentally
Ill Individuals Act
(PL-99-319)

May 10, 1988

The National Association of Private Psychiatric Hospitals appreciates this opportunity to express its views with regard to the federal Protection and Advocacy for Mentally Ill Individuals Act (PL 99-319), due for reauthorization this year.

The membership of NAPPH has always supported patient rights, and strongly believes in advocacy and protection for patients who are abused or mistreated in institutions. In fact, our strict membership criteria require that each member hospital have in effect written policies and procedures regarding patient rights.

In 1985 we supported legislation authorizing the current protection and advocacy program -- despite our initial opposition to the bill as originally drafted -- because the final version represented a rational and fair approach to a difficult issue, and was the result of many hours of deliberation, negotiation and compromise between providers of mental health services, consumer groups and advocates. We are prepared to support the program's reauthorization, but believe strongly that it would be premature to make substantive changes at this time. It is important to note that although the program was originally authorized for three years, it has only been in effect for eighteen months

-- hardly time enough to assess realistically how well it is working. In fact, it is our understanding that some of the State protection and advocacy agencies have not yet submitted their required progress reports to the Secretary "describing the activities, accomplishments, and expenditures of the system" in their State, due January 1, 1988.

Without knowing how well the current program is working, other than from anecdotal reports of isolated incidents, it would simply be unwise to make significant statutorial changes. Any such refinements to the program at this point would clearly be based on incomplete information and could further impede the States' efforts to complete implementation of the original Act. We are concerned, therefore, about several changes recently proposed by a coalition of advocacy organizations that appear to be based largely on such anecdotal information, and could jeopardize the delicate compromise reached in 1985.

For instance, the coalition seeks to strengthen the access provision by: 1) allowing advocates to participate in the hospital's discharge planning sessions; 2) allowing them to attend staff meetings in which reports of abuse and neglect prepared by staff are discussed; and 3) allowing them access to the records of "individuals who have died or whose whereabouts are unknown". These changes not only raise further questions about patient confidentiality, but would also create an additional administrative burden for the hospital, without necessarily improving the treatment or quality of care received by the patient. Moreover, giving advocates access to staff meetings would most likely have the undesireable and unintended effect of significantly inhibiting interaction and discussion among facility staff.

The coalition further seeks to expand eligibility for protection and advocacy services to include persons in the process of being admitted to a hospital. The 1985 authorizing legislation's original focus and intent was to protect a patient's rights while in the facility, and to protect him/her from any abuse or neglect during his/her stay in that facility. Including individuals who are in the "process of being admitted", without adequately defining that process, and without sufficent evidence to indicate the need for such an expansion, is unjustified and goes beyond the legislation's original intent. Furthermore, it is important to keep in mind that the Protection and Advocacy program has very limited resources with which to carry out even its current responsibilities. According to their recent testimony, State agencies are having a difficult time focusing their resources and priorities with the responsibilities they now carry. Many clients who deserve or need their services are not being served. Therefore, broadening the scope of the legislation by increasing access to facilities and patients not currently eligible for services is not only unjustified and premature, as discussed earlier -- it is also impractical.

A third proposed change with which we disagree involves the application process. Currently the protection and advocacy agency in each State must apply annually for its allotment, and the Governor must provide "assurances" that certain conditions are met. The coalition seeks to eliminate this process, and require the application and assurance process only when statutory changes require new or additional assurances, or when the Governor is planning redesignation of the agency. It is our view that the annual application process serves a necessary oversight purpose. Any new program can expect problems in its early stages, and oversight can be especially critical to its success. We recommend continuation of this process, at least until we have had a better opportunity to assess the program.

Despite our general view that it is premature to make substantive changes in the program, we believe some of the coalition's proposals may have merit. For instance, giving the advisory board -- made up of mental health professionals, providers of mental health services, individuals who are receiving or have received mental health services, and family members of such individuals -- an increased role in developing policies and priorities of the system, is a good idea. If the Protection and Advocacy program is to be effective, it is vitally important that those knowledgeable about the special advocacy needs of the mentally ill play a key role in the advocacy system.

We also support the coalition's proposal to include language recently added to the protection and advocacy title of the Developmental Disabilities Act, which would require the advocacy system to provide the public with an opportunity to comment on priorities established by the system. It would also establish a grievance procedure for clients or prospective clients of the system.

These last proposed changes are positive, and seek to improve the system through better communication among all involved parties. It is our belief that most of the problems experienced by the system thus far are due primarily to a lack of communication between advocates and facilities, and to unfamiliarity with the program. Rather than concentrating on statutorial changes that may or may not be necessary at this point in time, we should be encouraging better communication and input from all interested parties.

In conclusion, we are prepared to support continuation of the Protection and Advocacy for Mentally Ill Individuals Act with minor changes, such as those suggested above. However, we urge you to reject any efforts to make subtantive changes with regard to access to facilities until there has been sufficient time to assess the effectiveness of the current program. In fact, we recommend that the program be reauthorized **with no major changes** for a period of two years. By the end of that time it will have been in effect for just over the three years initially authorized, and we will have had a reasonable amount of time with which to evaluate its impact and effectiveness.

We look forward to working closely with you in formulating rational legislation to reauthorize the Protection and Advocacy for Mentally Ill Individuals Act.

Mr. **Silverstein**. Thank you very much.

The Subcommittee is adjourned.

[Whereupon, at 4:25 p.m., the Subcommittee was adjourned.]

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